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The Digital Transformation and the Right to Health of Young Adults in Bangladesh and Colombia: A Community-Engaged Study

DIGITAL HEALTH AND RIGHTS PROJECT CONSORTIUM

Abstract

In her 2023 report to the United Nations Human Rights Council on digital innovation, technology, and the right to health, the Special Rapporteur on the right to health underscored the positive impact of the digital transformation on young people, but also noted serious concerns, calling for greater efforts to consult and engage with youth and civil society. In our study, early-career researchers from Bangladesh and Colombia collaborated within a broader international research and advocacy project to investigate how diverse young adults experience digital health and to invite their recommendations and collaborative advocacy. Researchers held focus group discussions and interviews with young adults aged 18–30 (in Bangladesh, predominantly men; in Colombia, people living with HIV, gay men, and transgender women). In both countries, young adults said the digital turn had transformed their access to sexual and reproductive health and HIV information, highlighting both the positive role of young social media influencers and the harms caused by misinformation, lack of confidentiality, and widespread stigma. They called for greater government efforts to develop digital health, including through social media platforms. We find that transnational collaborations like this one offer the potential to generate actionable insights and inform the development of rights-based digital governance.

The Digital Health and Rights Project Consortium includes the BRAC University James P. Grant School of Public Health, Bangladesh, the Global Network of People Living with HIV (GNP+), Netherlands, KELIN, Kenya, Privacy International, United Kingdom, Restless Development, STOPAIDS, United Kingdom, the Universidad de los Andes, Colombia, and the University of Warwick, and is hosted by the University of Warwick, United Kingdom.

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Introduction

The digital transformation of health—including the integration of technologies and tools for health data management, telemedicine, artificial intelligence (AI)-driven diagnosis, mobile phone apps, and more into health systems—offers resource-constrained governments new ways to fulfill the right to the highest attainable standard of health. Yet related evidence of threats to privacy and autonomy, along with other harms, is accumulating.[1] Social media platforms are increasingly used to share sexual and reproductive health (SRH) information and for HIV prevention.[2] Systematic reviews have found that social media interventions are effective tools for the HIV response.[3] At the same time, the rapid growth and consolidation of power in social media sites, and the related spread of misinformation, have made these spaces challenging to regulate.[4]

The World Health Organization (WHO) defines digital health as "a broad umbrella term encompassing eHealth as well as developing areas such as the use of advanced computing sciences (in the fields of 'big data', genomics and artificial intelligence, for example)."[5] To address and develop digital health globally, in 2021, the World Health Assembly adopted a *Global Strategy on Digital Health 2020–2025*, which commits states to strengthening digital governance that upholds human rights, among other goals.[6] The *Global AIDS Strategy 2021–2026* also calls for intensified efforts to use digital spaces to reach people living with HIV and key populations (defined by WHO as gay men and other men who have sex with men [MSM], sex workers, people who use drugs, and transgender people).[7]

To strengthen the governance of digital health, United Nations (UN) agencies have promulgated new guidelines. These include guidance on the ethics and governance of AI; guidance on ethics and rights in the governance of technologies in the HIV response; and guidance on SRH and AI, to name a few.[8] In her 2023 report to the UN Human Rights Council, the Special Rapporteur on the right to health, Tlaleng Mofokeng, proposed the first normative framework for digital innovation, digital technologies, and the right to health, grounded in human rights standards.[9] This framework affirms that digital technologies "should improve the availability, accessibility, acceptability and quality of health services for all," highlighting the need to attend to opportunities for and threats to SRH in particular, and calling for governance to be grounded in the human rights principles of nondiscrimination, accountability, and privacy (see Table 1).[10] In particular, it emphasizes the right to participation in calling on states to "develop a regulatory environment with the participation of users," including young people.[11]

Globally, over a third of internet users are between 25 and 34 years old.[12] However, a review of national digital health strategies finds little evidence of either youth participation or attention to their specific needs.[13] The same is true of global health policy: while young people are often online and often the targets of digital health interventions, they are frequently left out of consultations, design, and policymaking, according to the first major review of global governance of digital health led by the Lancet and Financial Times Commission on Governing Health Futures 2030.[14]

Likewise—and perhaps relatedly—while an estimated 60% of the world's population uses social media, the UN guidance on ethics and rights noted above, and the WHO *Global Strategy on Digital Health*, do not address social media as a venue for digital health governance. To be fair, doing so is not a small challenge, particularly in relation to SRH. Most member states have little direct influence over powerful social media companies. Meta has three billion active users on Facebook, and many more on Instagram and WhatsApp—numbers that dwarf the populations of Bangladesh and Colombia combined.[15] The net worth of Meta's co-founder, Mark Zuckerberg, is estimated to be US$184.6 billion, roughly half the gross domestic product of Colombia.[16] Setting aside the power and influence of these agencies, managing SRH misinformation on social media raises complex challenges, given the need to protect the rights to freedom of expression and to quality health information in diverse social and legal standards on sexually explicit language and imagery.

To take on such challenges may require new thinking and collaboration. César Garavito-Rodríguez calls the digital transformation a threat to human rights that will require collaborative research and advocacy across national borders.[17] Mark Goodale similarly proposes that rights advocates set aside claims to universality in favor of "trans-local" alliances that cross boundaries of community or nation to confront shared challenges.[18] We have argued elsewhere that the digital transformation of health will require new collaborations and new approaches to knowledge production and advocacy that center the voices of advocates in low- and middle-income countries.[19]

To understand the experiences of young adults with the digital transformation of health, and establish a platform through which they might collaborate to promote their recommendations, we established an international consortium that has conducted collaborative research across diverse contexts through three related studies. Below, we briefly outline our consortium's approach, and then provide background on the study in Bangladesh and Colombia, before sharing our methods and findings.

Digital Health and Rights Project Consortium

The Digital Health and Rights Project Consortium (hereafter, Digital Health and Rights Project) includes human rights lawyers, social scientists, health advocates, and global and national networks of people living with HIV in 10 countries. Our research aims to draw on the lived experience of people living with and affected by HIV with documenting abuses (such as health sector discrimination and criminalization) and with effective local and transnational mobilization for policy impact.[20]

The co-founders of the Digital Health and Rights Project include civil society leaders engaged with the Board of the Global Fund to Fight AIDS, Tuberculosis and Malaria, who, together with social scientists, identified the need for policy recommendations about technology and health that could inform global health governance. We agreed to use participatory and community-engaged approaches to build capacity in national institutions to engage on the issues over the long term.

The project focused initially on Ghana, Kenya, and Vietnam, based on consultation by the Glob-

Table 1. Digital innovation, digital technologies, and the right to health

The 2023 report by the UN Special Rapporteur on the right to health draws on the normative framework provided by human rights law and consultations with member states, civil society, and experts to analyze emergent issues in the digital transformation of health that impact the right to health.	
Availability	Availability of health facilities, goods, and services supported by digital innovation and technologies
Accessibility	Accessibility of health facilities, goods, and services supported by digital innovation and technologies, understood as including • nondiscrimination • physical accessibility • economic accessibility • information accessibility
Acceptability	Digital technologies and the (cultural, linguistic, gendered, and generational) acceptability of health facilities, goods, and services
Quality	Digital technologies and the quality of digital health facilities, goods, and services
Sexual and reproductive health and rights	Digital innovation and technologies and the right to SRH; importance of addressing • expanded access to SRH care through digital technologies • surveillance • intrusive data collection • bodily autonomy
Right to privacy	Digital innovation, digital technologies, and privacy
Good practices	Global, regional, and national digital health governance
Participation	Importance of a participatory approach to digital health governance, including • transparency • accountability • access to remedy for harms

al Network of People Living with HIV (GNP+), a consortium member, with national networks. In 2021, with support from the Open Society University Network (OSUN), the Digital Health and Rights Project invited BRAC University and Universidad de los Andes to join, adding Bangladesh and Colombia to the list of focus countries. These five countries were thus selected by actors in each country based on their own interest to engage. Fortuitously, the five countries also represented five different geographic regions (West Africa, East Africa, Southeast Asia, South Asia, and Latin America, respectively), informing collective recommendations for global governance.

In all five countries, the project focuses on young adults either living with or affected by HIV, including key populations, and on training and mentoring young researchers and advocates in national institutions who use the research findings to engage in advocacy. To date, the Digital Health and Rights Project has undertaken three studies, including the one presented in this paper, which are interlinked as follows:

1. *Botnar One*. The first study, conducted in Ghana, Kenya, and Vietnam and funded by Fondation Botnar, was undertaken in 2021–2022 and applied a transnational participatory action research approach.[21] National researchers from study populations collaboratively led processes of training, consultation, data-gathering, and validation of findings in each country.[22] Based on focus group discussions with 174 young adults, as well as digital ethnography on social media accounts and key informant interviews, the Botnar One study team found that young adults relied heavily on social media for health information. Participants described learning from, or becoming themselves, social media health champions; they also disclosed online harms, issues with misinformation, and concerns about data protection. They called for more training on digital rights and a voice in governance. These findings and methods informed the next two studies.
2. *Botnar Two*. In 2022–2024, a second grant from Fondation Botnar funded Kenyan human rights group KELIN to lead an effort to support the Special Rapporteur on the right to health in producing her report on digital technologies, digital innovation, and the right to health, described above. This work included a literature review led by the Geneva Graduate Institute, as well as youth and civil society consultations led by KELIN, GNP+, and STOPAIDS (a UK health advocacy network) with human rights lawyers, health advocates, and young people in Africa, Asia, Europe, and Latin America. The civil society networks co-authored submissions to the Special Rapporteur and disseminated the final report and its recommendations in a series of public events.
3. *OSUN*. The third study, funded by OSUN, is presented in this paper. It was conducted during 2021–2023 by researchers from BRAC University in Bangladesh and Universidad de los Andes in Colombia and guided by a principal investigator from the Geneva Graduate Institute. The OSUN study began six months after Botnar One and included strong collaboration between the Bangladesh and Colombia researchers within the frame of the overall Digital Health and Rights Project. The objective of this study was to understand how young adults experience the benefits and risks of the digital transformation of health and to invite their recommendations for digital governance.

The first study, Botnar One, utilized a participatory action research approach, which required significant resources to complete.[23] For the third study, which had less funding and time available, the researchers decided to use a less intensive community-engaged research methodology.[24] They adapted the Botnar One research protocol, briefing community-led and youth-led organizations on it in local languages, and inviting advice on the study design. They rigorously reviewed the discussion question guides with community leaders to tailor questions to local contexts. The BRAC University team held a closing validation workshop with young people from the study in Dhaka. The Universidad de los Andes team and the principal investigator spent two weeks traveling to the offices of community-based organizations of people living with HIV and key populations in Bogotá and Medellín, which served to validate study findings and inform future research plans. Throughout, the BRAC and los Andes researchers participated in the larger consortium, which included researchers and groups engaged in the Botnar One and Two studies. Participation included weekly online research clinics that convened researchers from all of the study countries for training and experience-sharing; monthly calls with guest lecturers; and smaller working groups that planned public events. Further, the BRAC and Andes researchers presented on the OSUN study to the full Digital Health and Rights Project at an in-person meeting in Nairobi, Kenya, in 2022.

Civic engagement continued throughout and after the study. The BRAC team held two webinars in Bangla with national experts to discuss digital governance and SRH in Bangladesh.[25] The Colombian team held an in-person event to share and discuss findings with experts and community-based organizations of people living with HIV. After validation was complete, each national team provided microgrants to community-led organizations to support online advocacy and knowledge-sharing. The teams also shared the study findings at a workshop with UN and other stakeholders at the Brocher Foundation in Geneva, Switzerland, in 2023. Additionally, they participated in joint dissemination activities, including research presentations to the Global Fund, UNAIDS, and the Permanent Mission of Bangladesh in Geneva.[26] Because of this broader collaboration, we authored this paper collectively.

Before turning to the study methods, findings, and how these findings have been used in advocacy, we provide a brief overview of the two national contexts of Bangladesh and Colombia.

Bangladesh and Colombia

Bangladesh and Colombia are at first glance more different than they are similar. Bangladesh is a lower-middle-income country; Colombia is an upper-middle-income country. Over 90% of Bangladesh is Muslim; approximately 87% of Colombia is Christian (78% Catholic).[27] The countries have different languages, geographies, and histories.

However, as two low- and middle-income countries contending with the digital transformation, Bangladesh and Colombia share common challenges. First, both have rapidly growing young populations, who are increasingly online. Twenty-six percent of Colombia's population is between 14 and 28 years of age, and close to 80% own a mobile phone.[28] Likewise, in Bangladesh, an estimated 28% of the population is between 15 and 29 years; mobile phone ownership exceeds the size of the population.[29] In Bangladesh, the digital divide is gendered: less than a quarter of young women use internet, while the rate among young men is more than double, at 56%.[30] Nonetheless, in both countries, the digital turn offers the promise of efficiently reaching young people with SRH and HIV information and services.

Both Bangladesh and Colombia need to meet this challenge, as they have significant gaps in accurate SRH knowledge among young people.[31] In Bangladesh, Subas Biswas and colleagues find that a lack of knowledge and strict taboos on discussing sexual health are linked to risky sexual behaviors.[32] In Colombia, the leading national center for SRH, Profamilia, finds that poor implementation of education policies is one of the determinants of high adolescent pregnancy rates.[33]

Relatedly, both countries also face concentrated HIV epidemics among young key populations. Stigma and punitive laws create challenges to reaching these populations with information and services. HIV prevalence in Bangladesh has steadily increased since 1990, particularly among MSM and people who use drugs.[34] The criminalization of same-sex relationships, and related homophobic violence, may contribute to driving this population underground.

Colombia also has a concentrated epidemic, with growing numbers of AIDS-related deaths and high rates of HIV among transgender people.[35] Close to 30% of people living with HIV report experiencing either discrimination or denial of medical services in Colombia.[36] While same-sex sexual behavior is not illegal in Colombia, transgender women do confront epidemic rates of violence, and this has been shown to create considerable cultural barriers to accessing health services.[37]

Thus, in both countries, reaching young adults—and in particular, young key populations—with health information and services is critically needed. The digital transformation offers a means to circumvent the social barriers created by taboos, stigma, and violence. To do so will require targeted efforts.

In her report to the UN Human Rights Council, Mofokeng highlights the progress in many countries in developing digital health governance that upholds human rights. Such progress is evident in Bangladesh and Colombia, as the BRAC and los Andes researchers found in a comparative review.[38] They identified efforts in both countries to strengthen digital governance and data protection.[39] They also found gaps, including a lack of specific attention to SRH rights, youth needs, and data protection, as well as a lack of youth participation and consultation in digital health governance. In both countries, researchers found some uncertainty regarding limitations on the utilization and sharing of personal health data with third parties.[40]

As these efforts to strengthen digital governance and digital governance continue in Bangladesh, Colombia, and global health agencies, what do young adults in Bangladesh and Colombia experience as working and not working for them in the digital transformation of health? And if they were consulted, what insights would they offer? These are the questions we sought to answer in this study.

Methodology

Study population

The OSUN study population in Bangladesh and Colombia was intentionally identified in ways that were seen as consistent with and as extending the study population in the Botnar One study in Ghana, Kenya, and Vietnam. The age range had been earlier identified by the Botnar One study team as consisting of young adults between 18 and 30. Because the definition of "young person" varies among countries, the age range of 18–30 years was set across all five countries by the study team in the Digital Health and Rights Project based on consultation with global youth networks.

Within this common age group, each national team identified a focus population that fitted its own research expertise and future advocacy plans. In the Botnar One study in Ghana, Kenya, and Vietnam, researchers at the Ghana National Association of Persons Living with HIV opted to focus on young people living with HIV; the Vietnam Network of People living with HIV focused on young people living with HIV and key populations; and KELIN focused on young women in Kenya, given its ongoing work on SRH.

In the OSUN study, the BRAC team decided to focus on young men in Bangladesh, both to build on the team's prior research on young men and SRH and to complement the Kenya team's focus on young women.[41] The los Andes team focused on people living with HIV, MSM, and transgender people in Colombia.

In both Bangladesh and Colombia, national researchers used purposive snowball sampling, recruiting through established networks of student health advocates (in Bangladesh) and peer-led networks of people living with HIV, MSM, and transgender people (in Colombia). In Colombia, los Andes researchers advertised on social media platforms. In Bangladesh, given strict taboos and related security risks, the research team decided not to advertise the study publicly, instead recruiting through established networks.

Research methods

Research was conducted between April and September 2022 in Colombia, and between July and December 2022 in Bangladesh. The qualitative research design centered on focus group discussions and in-depth interviews with the study population, supplemented by digital ethnography on social media accounts and by key informant interviews, as follows:

- *Focus group discussions (FGDs) and in-depth interviews.* Researchers held FGDs with young adults in at least two cities in each country. The discussion guide explored where and how young adults obtain and share health information on mobile phones; their experience of the benefits and risks; their knowledge of digital health governance; and their recommendations for digital health development and policy. Researchers also held semi-structured one-on-one interviews with the study population to probe their experiences in more depth.

- *Digital ethnography.* To understand how young adults use social media to gather and share health information, researchers conducted participant observation on Facebook, YouTube, and Instagram, selecting those with active youth engagement on issues pertaining to HIV and SRH (based on numbers of likes and comments). The digital ethnography informed researchers' analysis of the FGDs.
- *Key informant interviews.* Researchers conducted semi-structured interviews with experts to gain insight into the current governance of digital health in each country. These included community leaders; leaders of health advocacy organizations and health tech companies; and human rights scholars. The interviews explored progress and challenges in national digital health governance in light of the emerging benefits and risks identified by FGD participants. The timing and location of interviews were scheduled at the convenience of respondents. Interviews ranged in length from 30 to 120 minutes. These interviews informed researchers' analysis of the recommendations by young adults.

Data analysis

All interviews were recorded in Bangla or Spanish, transcribed, and translated into English. A team of seven researchers from BRAC University, Universidad de los Andes, and the Geneva Graduate Institute analyzed transcripts on Dedoose. They utilized the codebook from the Botnar One study, reviewing and adding concepts identified based on an initial reading of the transcripts from Bangladesh and Colombia. A second coder reviewed each transcript, and differences were discussed in weekly online meetings to reach agreement. The draft findings were then presented to study participants for discussion as noted above.

Ethical considerations

Ethical concerns included the risk of public exposure for study participants given the above-noted stigmatization of sexual activity (in Bangladesh), and sexual orientation, gender identity, and HIV status (in both countries). In Bangladesh, there was additional risk that either researchers' or participants' views might be interpreted as critical of the government. Ethical approval was sought and obtained from ethics review boards in Bangladesh, Colombia and Switzerland, with details provided at the end of this paper.

While participants were recruited through established networks of people living with HIV, MSM, and transgender people, we did not ask individual participants to identify their sexual orientation or HIV status; some did volunteer this information. All participants were anonymized using codes. All participants provided written informed consent. Data were stored on locked, secured drives and shared using only encrypted sites.

Results

In total, 118 individuals were interviewed—60 in Bangladesh and 58 in Colombia (see Table 2):

- *FGD participants in Bangladesh.* BRAC researchers held eight FGDs in Bangladesh (three FGDs in Manikganj, three in Bagerhat, and two in Dhaka) with 49 participants. Given the BRAC team's focus on young men, most study participants were male and between the ages of 18 and 24, apart from a few young women who joined in Bagerhat to share their perceptions of their male partners' SRH practices. Most participants were university students, with a few development workers, nurses, and businesspeople. Researchers held one FGD with a support group of gay male, non-binary, and transgender young adults in Dhaka; for security, this was held online.

- *FGD participants in Colombia.* The los Andes team conducted four FGDs in Medellín and one in Bogotá, with 26 participants. Participants included 24 men and two non-binary people. Despite ongoing efforts, the recruitment of women below 30 years of age proved challenging. Leaders of support groups of women living with HIV attributed the low response rate to pervasive HIV-related stigma and slut-shaming. The Colombian FGDs included students and professionals, including administrators, auditors, architects, instructors, and several unemployed people; many identified as AIDS activists. Most FGDs took place in the offices of nongovernmental organizations. One FGD was held online at request of the community organization supporting mobilization.
- *In-depth interviews.* In Bangladesh, researchers conducted four in-depth interviews: one with a project officer from a nongovernmental organization, one with an Ayurvedic medical practitioner, and two with students. In Colombia, to address the gap in female recruitment, researchers conducted a group interview with nine women living with HIV over 30, and a small-group interview with five transgender women over 30 in Bogotá, three of whom identified as sex workers.
- *Key informant interviews.* In Bangladesh, researchers conducted seven key informant interviews with editors, digital health professionals, health service providers, and legal scholars (see Table 3). In Colombia, researchers conducted 18 key informant interviews with digital health experts, health rights advocates, online editors, health service providers, civil society directors, community leaders, human rights experts, and transwomen community leaders living with HIV.

Results

Availability, accessibility, acceptability, and quality

Study participants in both countries expressed enthusiasm for the use of digital spaces, including community-developed mobile health apps, to access SRH information, but said that Google and social media were their main sources.

In Colombia, TeCuidamos, an HIV web platform supported by EnTerritorio, a state agency, and funded by the Global Fund, links users to HIV information and services such as tests and condoms. In Bogotá, an interviewee involved with TeCuidamos described conceiving the idea during

Table 2. Distribution of interview participants by gender and location

Country	District	Gender	Focus group discussions	Key informant interviews	In-depth interviews	Subtotal	Total
Bangladesh	Dhaka	Male	11	6	4	23	60
		Female	0	1	0		
		Chose not to disclose	1	0	0		
	Manikganj	Male	20	0	0	20	
		Female	0	0	0		
	Bagerhat	Male	9	0	0	17	
		Female	8	0	0		
Colombia	Medellín	Male	19	6	0	38	58
		Female	0	2	9		
		Trans woman	0	0	0		
		Non-binary	2	0	0		
	Bogotá	Male	5	7	0	20	
		Female	0	3			
		Trans woman	0	0	5		
		Non-binary	0	0	0		

the COVID-19 pandemic:

> *I said, well, what is happening in the pandemic? How do you order food? Through an app. How do you order a cab? Through an app. In other words, all these through an app.*

Bangladeshi participants similarly identified several locally developed apps as valuable sources of Bangla-language health information and services.

However, many participants in both countries said that Google searches and social media had become equally—if not more—important spaces for accessing youth-friendly health information. They emphasized that the anonymity afforded by these digital spaces enables the avoidance of slut-shaming, transphobia, homophobia, and HIV-related stigma by health care workers. In Manikganj, Bangladesh, MNK-FGD1-D04, a 19-year-old male student, said, "If I go to the central hospital with a sexual problem, I don't think they will examine it carefully. They would not even look at me." On social media sites, by contrast, he said, "I feel my confidentiality is maintained. It's a blessing." In Bogotá, BOG-KII-I, a 33-year-old transgender sex worker, said:

> *Sometimes out of fear, or fear of going to an establishment where you are going to be treated badly, where you are going to be discriminated against, where you are going to be violated—you are like, "Oh, no, I better ask by WhatsApp."*

Thus, study participants in both countries said that trusted content creators on social media had become important sources of information and personal advice. In Colombia, men recruited through networks of MSM living with HIV referenced peer-led social media accounts such as Más Que

Table 3. Key informant interviews by gender, age, and occupation

ID number	Gender	Age	Employment
Bangladesh			
DHK-KII-A	Male	29	Legal coordinator and trainer
DHK-KII-B	Male	26	Health technology brand manager
DHK-KII-C	Male	35	Fact-checking editor
DHK-KII-D	Male	34	CEO of health technology company
DHK-KII-E	Male	47	Director of medical services
DHK-KII-F	Male	33	Academic law expert
DHK-KII-G	Female	25	Founder of health site
Colombia			
BOG-KII-A	Female	Over 40	Coordinator of a digital intervention
BOG-KII-B	Male	Over 40	HIV activist
BOG-KII-C	Female	28	Coordinator of digital intervention
BOG-KII-D	Female	Over 30	HIV activist
BOG-KII-E	Female	Over 30	Coordinator of a digital intervention
MED-KII-A1	Female	25	SHR podcast
MED-KII-A2	Male	26	SHR podcast
MED-KII-B	Male	Over 40	Lawyer and HIV activist
MED-KII-C	Female	Over 40	Coordinator of a digital intervention
MED-KII-D	Male	27	HIV activist and YouTuber
MED-KII-E	Male	29	HIV activist and Instagrammer
MED-KII-F	Male	32	HIV activist
MED-KII-G	Male	Over 50	Coordinator of NGO defending people's right to health
MED-KII-H	Female	Over 30	Woman living with HIV
MED-KII-I	Female	Over 30	Woman living with HIV
MED-KII-J	Male	Over 40	HIV activist
MED-KII-K	Transgender woman	30	Sex worker and activist
MED-KII-L	Transgender woman	26	Transgender woman living with HIV

Tres Letras and RASA. In Bangladesh, participants praised Tasnim Jara, a medical student who shares health information in Bangla through YouTube videos. Such intermediaries make SRH information not only available and accessible but acceptable to young adults by making the information and advice less stigmatizing and youth-friendly.

Study participants also described how free access to social media platforms had empowered them to become content creators themselves on HIV and SRH ("micro-influencers") to inform peers, combat stigma, and, in some cases, generate extra income from donations. In Medellín, MED-KII-D, a 27-year-old TikToker and YouTuber living with HIV, recalled:

> *On the 4th day [after HIV] diagnosis, I got up and I said "no more" … I am going to make money out of this diagnosis. And then from there it came out—my YouTube channel.*

Unsurprisingly, the reliance on web searches and social media was linked to concerns about misinformation. In Dhaka, DHK-IDI-4, a 19-year-old male student, provided a checklist of steps he follows to evaluate health information on Facebook:

> *I look at [content quality] first, ok? Then, [number of] views come as part of the Facebook algorithm, ok? And mostly, I read the comments. How many negative comments are there, which is good, and which is bad. I look at these things.*

Stigma on social media

Given the persistent stigmas and taboos described above, participants expressed anxieties about their online engagement. Some felt that community-led social media groups were hostile to them. In Medellín, cisgender women living with HIV described joining WhatsApp groups for people living with HIV but then leaving these groups after finding the exchanges to be dominated by young gay men who used sexist language. Likewise, transgender sex workers interviewed in Bogotá described WhatsApp groups as important for psychosocial support but said that some community members had encountered transphobic verbal abuse in such groups.

In Bogotá, BOG-FGD5-F, a 26-year-old unemployed man, described how HIV status is used to verbally attack MSM on social media:

> *If I know John Doe's diagnosis, then I go and put it on Facebook, or I put it [on] Grindr … his reputation goes down, because: "Ah yeah, the [homophobic slur] has HIV."*

In Bangladesh, a BRAC researcher conducting digital ethnography on Facebook identified Bangla-language accounts that actively promote the targeted harassment and slut-shaming of young women online.

Some Bangladeshi participants worried that even clicking "like" on an informative post about SRH might inadvertently expose the user as sexually active to others in the community. In Manikganj, MNK-FGD1-D02, a 19-year-old male student, suggested:

> *If I react to a post on a Facebook page which provides information on sexual health, advertisements on sexual health awareness will automatically go to one of my younger brothers [who is on my friends list]. Then he would say, "Brother has liked this type of page. Maybe he has sexual problems."*

MNK-FGD1-D03, a 24-year-old male student in the same focus group, agreed:

> *If I like that page [on SRH on Facebook], my friend or senior brother will not know with what intention I liked that page. I don't want others to know about my problems.*

The increasing need for access to mobile phones for the health system also was seen as creating new risks of privacy breaches. In Medellín, MED-FGD3-D, a 21-year-old non-binary student, recalled how their HIV diagnosis was sent electronically to their parents without the patient's permission, describing this as a confidentiality lapse in the health system. In Medellín, a female activist in her thirties living with HIV said that many women living with HIV may have to share smartphones with other family members, and face concerns about protecting medical confidentiality from the family when making medical appointments.

Participant recommendations

BRAC and Andes researchers asked FGD participants to share policy recommendations for the development and governance of digital health. Overall, participants called on government to do more to promote access to SRH information online, address misinformation, ensure digital inclusion, and address privacy and data protections. Participants in both countries were overall enthusiastic about digital health—but understood this as largely referring to web platforms and social media.

In Bangladesh, many of the young male FGD participants affirmed a strong interest in seeing the government promote digital health and share SRH information online in accessible and youth-friendly language. They called for more online information portals, workshops, and educational videos. DHK-FGD1-D01, a 22-year-old male student in Dhaka, imagined an online database, "so that if we need help … we can seek help from there, as [it is] not available in our families." MNK-FGD3-D15, a 20-year-old male student in Manikganj, said that online SRH resources were needed to "dismantle awkwardness, … and [young people] should be encouraged to denounce the taboo around [SRH]." Another FGD participant commented that he had heard of many health programs for young women but few for young men.

Bangladeshi FGD participants further urged public health agencies to engage more effectively with social networks and social media to reach young people with health information. DHK-FGD1-02, a 20-year-old male student in Dhaka, recommended that health officials leverage networks of male friends to reach their peers. He said:

> *If [young men] know about this information, they can tell their friends, "There is information about this here. Search here. Go here. There you will receive the proper knowledge."*

In Dhaka, DHK-FGD2-D02, a 20-year-old male student, proposed that health authorities partner with social media influencers interested in health, such as Tasnim Jara:

> *If one or two of her videos were pinned on the page of DGHS [Directorate General of Health Services], or renowned faces like her in Bangladesh, whom everyone knows, whose videos people watch, whom they follow; if videos of two or three of them could be pinned above the page or featured on the sides, then I think people would engage more.*

Others in the same focus group agreed with this participant, echoing his call to partner with Tasnim Jara.

Bangladeshi FGD participants also urged the government to do more to regulate health mis- and disinformation on social media. Some noted that the government has engaged in sweeping actions to suppress information classed as violating the Cybersecurity Law and asked why similar efforts have not tackled health misinformation.

However, BRAC researchers interviewed legal and civil society experts in Bangladesh who were understandably cautious about the complex legal challenges this would raise. In considering this challenge, DHK-KII-F, a legal scholar, posited a hypothetical case in which one lawyer alleges that SRH information is vulgar and should be suppressed, while another claims that it is educational, concluding:

> *The judge will be in conflict. In whose favor will the judge give [the] verdict? So you see the problem? So those who were drafting the law, I mean there's a lot lacking … If the laws are not properly defined, you cannot get proper justice … I would say we need a [Sexual and Reproductive Health and Rights] Act.*

Other experts on digital health in Bangladesh shared similar concerns that any government effort to regulate health misinformation could lead to censorship. Some proposed alternative solutions, such as a licensing system to award credentials to reliable online health information providers; or a multistakeholder civil society, academic, and government panel to review cases of alleged health misinformation. However, all agreed with the young FGD participants that more needed to be done. DHK-KII-D, the CEO of a local digital health company, warned that if the government fails to act, future harms or deaths resulting from health misinformation online would undermine public trust in the digital health industry.

Colombian study participants expressed concerns about the need to address the financial barriers to digital inclusion for people living with HIV, in order to ensure their access to health information and services. MED-KII-G, a 50-year-old male HIV activist in Medellín, commented that clinics have subsidized transportation costs for clinic visits, and he recommended that these subsidies be used today to finance digital access:

> *Telemedicine … should be a progressive, incremental gain, even financed in some circumstances. For example, if you are not going to pay transportation to a user and that user does not have connectivity, then you subsidize connectivity, just as you subsidize transportation, yes? Pay them at least a data plan of 20,000 pesos [approx. US$5] per month.*

Several transgender study participants raised concerns about the lack of recognition of gender identity change in Colombia's eHealth systems and urged patient databases to recognize these changes. As a good practice, one transgender sex worker recommended Yana, a Latin American mental health app that offers non-binary gender categories and pronouns.

In Colombia, FGD participants emphasized the need for greater efforts to protect privacy, which may reflect the fact that most of these study participants were living with HIV or from key populations. Colombian FGD recommendations included calls to better regulate Facebook to limit the sale of health information to third parties, and more stringent regulation of health data privacy in the formal health system. Participants in Colombia raised concerns about data on their online activities being used in court cases on intentional HIV transmission. In Bangladesh, experts we interviewed also recommended the reform of data protection laws to treat personal health data as sensitive and restricted. At the same time, participants' views on privacy were complex; many participants in both countries expressed resignation that their information online would be sold without their consent but wanted more transparency on where and how their information would be used.

Overall, FGD participants in both countries described themselves as reliant on their phones and comfortable with the digital transformation of health. However, when asked how their data are managed, who has access to these data, and how they are protected, most had little to no information. In Medellín, a 30-year-old male social media director, MED-FGD3-B, echoed the views of others we interviewed when he said:

> *Because of my [occupation] as a team leader, I am aware of the rights that my employees or collaborators have regarding their health issues, but I don't know how the health care companies or the Ministry of Health or the government protect my data, for example. I have no idea.*

In Bangladesh, most study participants described themselves as lacking basic knowledge about existing data or digital governance. In Bagerhat, BGT-FGD2-D08, a 26-year-old unemployed man, called for more public education on the existing laws.

Discussion

Overall, the study reaffirms the robustness of Special Rapporteur Mofokeng's normative framework, which interprets core elements of the right to health in the context of the digital transformation. While the study is limited by a gender imbalance among participants, its findings resonate with findings from our concurrent participatory action research study in Ghana, Kenya, and Vietnam on the same questions, which did include more young women. In both cases, it emerges that the growth of social media and access to mobile phones extends the availability, acceptability, and accessibility of health information and services, while creating additional challenges for rights-based digital health governance.

In particular, our findings point to a gap between the existing norms of digital health governance, which focus narrowly on eHealth and mHealth interventions within the control of national health ministries, and the broader real-world context in which young adults access health information. Young adults in Bangladesh and Colombia report that their experience of digital health is mediated by privately-owned web search platforms and social media accounts that are largely beyond the control of authorities of either country. In both Bangladesh and Colombia, two quite different contexts with very disparate religious and cultural norms, we found young adults strongly preferring young social media content creators over credentialed health experts because of the ability of the former to communicate in youth-friendly, non-stigmatizing, and nonjudgmental language.

While this study population was made up largely of young men, with smaller numbers of cisgender and transgender women and non-binary people, this finding is consistent with results from the Botnar One study in Kenya, Ghana, and Vietnam, which did engage young women in larger numbers; there, too, young adults reported heavy reliance on Google and social media for health information and peer support.[42]

The findings also emphasize an observation from the Special Rapporteur's report: that the rise of social media offers special opportunities for promoting SRH information to marginalized groups, such as young MSM and young transgender people, who may otherwise avoid formal health settings to avoid stigma. This shift to social media as a source of health information, however, exposes marginalized young adults to new risks of misinformation and stigma.

Thus, in the context of the right to health, the lack of regulation of social media content creators on health may facilitate free expression, enhancing the *availability*, *accessibility*, and *acceptability* of SRH information for young adults; still, this shift creates significant threats to the *quality* of health information. To address this challenge, study participants urged their governments to develop new approaches—namely, to partner with social media influencers to train and credential them, and thus reach young adults with reliable information. We strongly encourage states to consider this recommendation. Such partnerships, including training and official accreditation, could enhance the credibility, standing, and effectiveness of social media influencers and micro-influencers working in the public interest and enable health officials to reach otherwise hard-to-reach young adults. Governments should also seriously consider the practical proposal from key informants of forming multi-stakeholder panels with human rights, health, and civil society experts to collaborate and address health misinformation.

Other recommendations from young people in the study are practical, sensible measures that merit further discussion, such as the recommendation to provide subsidies to cover airtime and mobile phone costs to facilitate access to health information and services. The call by transgender women for gender-diverse eHealth platforms, if taken up, could help Colombian health officials reach transgender people with health information and services and help bring down rapidly escalating HIV rates in this key population. In both countries, governments could also expand the impact of existing data protection standards by promulgating digital governance and data protection rights more widely to ensure that young adults know their rights and where to turn if their rights are violated. All these measures could help improve public trust in digital health.

This study has highlighted some ways that listening to young people can shed light on real-world challenges, generating practical solutions. It also shows the potential of what Goodale calls "translocal" research and advocacy.[43] Youth and civil society consultation and participation in the study both enriches the findings and recommendations and has effectively helped shape "upstream" norms through the Digital Health and Rights Project's support to the mandate of the Special Rapporteur.

Learning from this and the previous studies, we have now formed a larger participatory action research consortium, with community advisory teams of 12 diverse young people in each of the focus countries in our study, including some former study participants, HIV activists, and digital rights activists who are collaborating with national research teams to dive deeper into the issues and advocate globally and locally. They are also contributing to collaborative work with WHO to analyze national digital health strategies and how these should address gender, equity, and rights.

UN agencies and donors should support the growth of similar participatory and community-engaged approaches with technical guidance and capacity-building resources and should include more youth and civil society representation in digital health strategy and policymaking processes. We see an important role for UN platforms to establish new norms for rights-based digital governance that consult young people about the challenges they face with the digital transformation, and to mobilize action.

Contributors

The following members of the Digital Health and Rights Project contributed to this paper:

- Md. Tanzirul Alam (BRAC University) contributed to data-gathering.
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- Sara L. M. Davis (University of Warwick) contributed to study design, literature review, data-gathering, analysis, project administration, writing, review, and editing.
- Afrida Faiza (BRAC University) contributed to literature review, data-gathering, and analysis.
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- Syed Hassan Imtiaz (BRAC University) contributed to literature review and data-gathering.
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