

TOWARDS DIGITAL JUSTICE:

Research insights into young people's experiences as technology transforms access to health services and support

This brief draws on the findings and recommendations from 18 months of research led by the Digital Health and Rights Project (DHRP)^{1,2}. DHRP brings together anthropologists, human rights lawyers and civil society, including networks of people living with HIV and youth activists. The researchers spoke to over 170 young people (aged 18-30) **across 7 cities³ in Ghana, Kenya and Vietnam⁴** to understand:

- How do young people experience and manage the effects of the digital transformation on their equity, autonomy, privacy and equality?
- What are the empowerment potential and risks linked to these new technologies?
- Who is shaping the digital agenda in health?

The researchers also reviewed and analyzed laws and policies, conducted digital ethnography in online spaces (Facebook, WhatsApp, TikTok, Instagram and Zalo) and interviewed 33 UN officials, government officials, tech leaders, social media influencers and community leaders in all three countries. Data was analyzed thematically and the results were presented to study participants for discussion. We used participatory action research, an approach in which community members participate in designing the study, gathering data, and analyzing results for action.

I work through the phone. I use the phone to communicate with relationships. I think the phone is also controlling a part of my health as well as my spirit

22-year-old woman, Vietnam



Limitations: While the young people in this study represented diverse genders and backgrounds, most lived in urban areas and had regular online access. Further research should explore these issues in more diverse populations of young adults.

I created an online family where I learnt and gained a lot of useful knowledge



27-year-old woman, Kenya

[1] This project has been funded by Fondation Botnar www.fondationbotnar.org

[2] Digital Health and Rights Project Consortium. (2022) Digital health and human rights of young adults in Ghana, Kenya, and Vietnam, Final Project Report

[3] In Kenya: Nairobi and Kisumu. In Vietnam: Hanoi and Ho Chi Minh City. In Ghana: Accra, Kumasi and Tamale. Vietnamese focus group discussions were conducted online due to Covid-19 restrictions.

[4] DHRP are currently undertaking further research in Bangladesh and Colombia, with the support of BRAC University and the University of Andes, which will inform future recommendations from DHRP.

1 KEY INSIGHTS

- Young people reported preferring **Google** and **social media** as a source of information about their health and of peer support.
- For many young people, the digital transformation in health is **empowering**. It gives them anonymous access to HIV, Covid-19 and sexual and reproductive health information they urgently need, but feel unsafe seeking elsewhere. It offers free space to innovate, and access to 'online families' who provide help and life-saving support.
- However, the online world is **deeply unequal**. Inequalities such as gender, race, class, geography and other factors shape the design of and access to digital tools and technologies, and the experience of users. Though women seek health information and share it with others, many struggle to afford smartphones and airtime.
- The digital transformation brings **risks to privacy, wellbeing and security**. Many participants worried about health **misinformation**. We found **digital governance** to protect against these threats is weak at national and global levels.
- **Digital justice** is about radically **shifting power** to young people – including women and people from marginalised communities, such as those living with HIV, sex workers, people who use drugs, migrants, and men who have sex with men – and enabling them to harness the positive potential of digital technologies to fulfill their human rights.
- We recommend **funding local initiatives** that put young people, in all their diversity, at the centre of design and policy-making that affects their lives

The anonymous quotes in this paper are drawn directly from young people and key informants in the research.

[5] World Health Organization (2018) Classification of Digital Health Interventions 1.0: A shared language to describe the uses of digital technology for health.

[6] Pifer R (2022): Digital health funding reaches record \$29.1B in 2021. Healthcare Dive

[7] For example, UNDP (2021) Guidance on the Rights-based and Ethical Use of Digital Technologies in HIV and Health Programmes; WHO (2021) Ethics and Governance of Artificial Intelligence for Health.

2 THE DIGITAL HEALTH TRANSFORMATION AND ROLE OF SOCIAL MEDIA

Digital health commonly refers to a range of information and communication technologies used in health systems, from mobile applications to artificial intelligence, health management information systems, telemedicine and more.⁵

Based on our research, we argue that 'digital health' should include social media (Twitter, Facebook, WhatsApp, TikTok and others) and search engines (Google), as many young people told us they prefer these sources for health information and services.


The digital transformation in health is accelerating rapidly, a change catalyzed by the Covid-19 pandemic: digital health saw over \$29 billion⁶ in new investment in 2021 in the US alone. Digital tools can broaden access to and improve the quality of health services, giving people greater control over their health and well-being. Global health agencies support the digital transformation to achieve the Sustainable Development Goals, including Universal Health Coverage. This is reflected in the World Health Organization (WHO)'s [Global Strategy on Digital Health 2020-2025](#), new UN guidelines on digital health and artificial intelligence,⁷ and new partnerships between health agencies and technology companies, such as the Global Fund's partnerships with Microsoft, Google Cloud and Zenysis Technologies.

However, the digital transformation brings risks that are particularly acute for young people, especially women and the most marginalized. While regulation is growing stronger in the European Union, the three countries we studied share weak legal and regulatory environments, a lack of community voice in decision-making, and social and economic inequalities that affect

access to the internet and smartphones. Young people's data is extracted for the benefit of private companies in high-income countries, a new form of 'data colonialism'.⁸

A major finding of our study was that **most young people reported relying on Google searches, social media, or social chat groups for health information and peer support.** Many officials we interviewed were unaware of this, and the WHO Digital Health Strategy does not discuss social media. This new trend brings benefits and risks, discussed below.

3 EMPOWERMENT POTENTIAL BUT RISK OF MISINFORMATION




I can use my phone without being judged, like I can access some information without worrying someone is noticing

27-year-old woman, Kenya

Young people in the study overwhelmingly expressed enthusiasm for the digital transformation in health, describing it as empowering, and expressing hope that it can also create new spaces for solidarity, collaboration and innovation. At the same time, many struggled to manage conflicting health information online.

Young women reported that they often use their mobile phones to look for information on HIV, Covid-19, and sexual and reproductive health information, including topics such as menstrual health, contraception, abortion information and pregnancy advice. Men said that they were less likely to do so and noted that there are few dedicated digital health apps that specifically address men's health, creating a disparity in services.

In Vietnam, young people living with HIV used Zalo (a social chat app like WhatsApp) to help one another access life-saving treatment, food, and financial support during lockdowns. In Kenya, peer outreach workers held regular group calls on WhatsApp to share information, sometimes with invited experts. Gay men in Ghana, who could not meet in person due to safety concerns, used chat groups to check in on safety of peers, and remind those to get refills of pre-exposure prophylaxis (PrEP) medication.



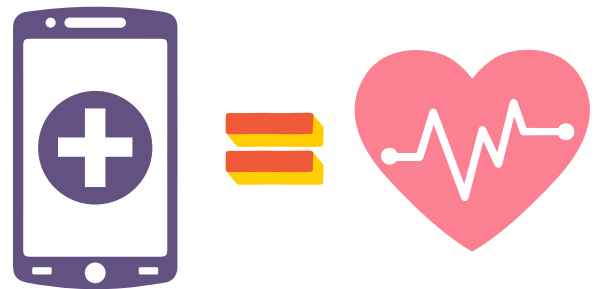
I have received numerous health tips because I had a WhatsApp contact ... and said 'Hey this is the situation. How do I go about it?' Then somebody says 'Okay, doing A-B-C-D will help

25-year-old man, Ghana

However, many young people told us that they struggle to sort through conflicting health information online. Some described serious instances of misdiagnosis and related harms.

Many described trusted networks and experts as key to helping them navigate conflicting advice online.

Social Media Champions



In line with their increased use of mobile phones for many aspects of daily life, young people described creatively using social media and chat

[8] Couldry N and Mejias U (2019). The Costs of Connection: How data is colonizing human life and appropriating it for capitalism. Stanford University Press.

groups to share information and advice on sexual and reproductive health and sexuality. In Vietnam, for example, a popular young doctor shares health information with key populations on YouTube, using catchy images, short clips and easy-to-understand answers to frequently asked questions.

Love Matters Kenya, a Facebook group, has amassed 1.8 million followers for advice and debate on sexuality and sexual and reproductive health.

According to the group's manager, Facebook's detailed data on users enables the group to tailor its messages. She emphasized the importance of youth-friendly imagery and language, and of alternating playful posts and questions with serious health-focused content in order to deliver accurate, sex-positive information to young people.

Respondents said that trusted peers, safe spaces and relevant languages were key to engaging young people. They also emphasized the importance of offering links to trusted in-person counselling providers.

On SHE+, we have ten different languages. Before you call, we already know what language you are going to speak. We assign someone who will probably greet you in the same language, so that you are much more comfortable to talk about your issues.

Savana Signatures Project Manager, Ghana

4 ISSUES AND CONCERNS

When you lose your phone, it's like you no longer exist

23-year-old woman, Ghana

Young people described the digital transformation as sweeping them into a rich, potentially rewarding, but risky online life. Those with the education, confidence and skills to navigate the online world said they rely on mobile phones as a source of health information, advice, and services, as well as psychosocial support. However, while many said privacy was crucial, most had little knowledge about how their data is used for profit by social media, or how to protect their security.


Specific issues raised by young people included the following:

- Challenges to equality and **digital divides**: "Young people need to be trained [in] knowledge and skills related to information security... They need to know how and where to find information such as PrEP, or HIV information" – 22-year-old man, Vietnam.
- **Mental health concerns** relating to over-dependence on mobile phones: "I get so attached to my phone that I forget to eat" – 22-year-old woman, Ghana.
- Risks and experiences of **online and offline harm** (misinformation, cyberbullying, lack of data protection/security, risk of exposure and physical abuse), lack of redress, and need for digital literacy: "When someone comes out as LGBT they will not only troll you, but also your family, which will greatly affect you" – 29-year-old woman, Kenya.
- Concerns about **surveillance** by private companies and police: "I can say we're being

controlled by someone behind the Google account...there is someone behind there who goes in our information” – 24-year-old man, Kenya.

Each of these issues is explored further below.

Digital Divides




Apps are creating invisible injustice between people...because there are people who don't use smartphones, and apps are creating distance for the poor who can't access basic needs

30-year-old man, Vietnam

While the digital gender divide has been widely documented, the focus group participants described this divide as intersectional in nature, complicated by diverse forms of inequality. In all three countries, women shared challenges with access that ranged from family pressures, lower income and lack of ability to afford smartphones and data, and concerns about online harassment. In addition to the gender dimension, many focus group participants shared concerns about uneven digital access for young people in rural areas, as well as for young people with less education, those who spoke diverse local languages, persons with disabilities, and older people.

Mental Health Concerns




During Covid period, many people had mental issues, and some of them ended up killing themselves. I can say [a mental health app] really helped me

23-year-old man, Kenya

Young people in the study strongly emphasized their concerns about their own mental health due to a perceived high degree of dependence on mobile phones, which had increased during Covid-19 restrictions. They described this dependence in emotional terms, mentioning feelings of addiction, of using their phones so much that they lose touch with their surroundings, even missing exams. Several said they felt that they did not exist without their phones, describing lack of a phone as a kind of social death.

Risks and experiences of online and offline harm



[If] I post, like, on Facebook, WhatsApp or Instagram, that I am suffering from this illness, what do you think people will say? People will throw words at you, nobody is willing to help you because you see these eyes that are looking at you here, there is no friend here.

25-year-old woman, Kenya

Online communities may be lifesaving for some; however, focus group participants reported harm linked to using digital platforms, including censorship, bullying, extortion and offline violence. Participants in all three countries also reported cyberbullying linked to seeking health information, coming out as LGBTQ+ online, or championing sexual and reproductive health and rights. Women especially reported frequent experiences of sexual harassment online. Sex workers reported being blackmailed by former clients with their intimate images, and said reporting this to the police exposed the sex workers to risk of arrest themselves.

Surveillance and data extraction

Participants worried that their private health information was being sold to third parties without their knowledge or consent. Others worried that

online searches could expose them to the risk of arrest or exposure, for instance as a young woman seeking an abortion in a country where abortion is illegal, or as a gay man. Many expressed an interest in learning more about their digital rights.

Gaps in Accountability

I think that groups of young people living with HIV or young key population communities ...do not have much say in building health applications.



21-year-old male, Vietnam

Globally, digital governance is at an early stage of development. While numerous ethical standards and guidelines have been produced, we found little awareness of these at national levels.

Ghana is currently developing a national digital strategy, but this does not address health. Kenya lacks a comprehensive legal framework, relying on a patchwork of different standards which are not well enforced. In Vietnam, authorities rely on a Cybersecurity Law which does not address the issues outlined above. We found no national coordination mechanisms for digital health in any of the three countries, resulting in overlaps and duplication of digital health apps. We also found no instances of youth participation in digital governance. Rather, private sector companies were shaping draft laws and policies.

The Lancet and Financial Times Commission on Governing Health Futures 2030⁹ calls for young people to be at the centre of digital governance. Participatory action research offers one way to empower young people to contribute. Investing in local digital health solutions including partnering

with local social entrepreneurs with young followings could be one means to resist data colonialism while strengthening health systems.

5 RECOMMENDATIONS

I want the government to listen more, especially to young people like us. We have different needs and thoughts than 30 to 40 year olds



26-year-old male, Vietnam

A rights-based approach to digital technologies in health must be built on the meaningful participation of civil society and communities – including young people in all their diversity – in national and global governance of digital health. It is therefore important that **health advocates of all ages and civil society mobilise to promote digital rights**, using an intersectional lens that addresses diverse forms of digital inequality.



Action by UN agencies, donors and national governments will be essential, as outlined on the following page:

[9] The Lancet and Financial Times Commission on Governing Health Futures 2030: Growing up in a digital world (2021). The Lancet, Vol. 388, No. 10312 (October 24).

Key Actors



UN and other global health agencies



Donors
(including Global Fund,
bilateral donors, private
foundations)



National Governments

Recommendations

Commit to rolling out existing guidance on ethics, human rights and digital health at national levels, including training and technical support to country offices and member states

Develop and promote new guidance outlining the norms, laws and policies that need to be in place for states to respect, protect and fulfil human rights with the use of data and technology in health. This should include the meaningful participation of civil society and communities in decision-making

Develop a set of evidence-based interventions to address digital divides and digitally empower young people

Recognise web searches and social media in the definition of digital health

Fund interventions that digitally empower communities, including:

- digital rights and literacy training for communities, government and healthcare providers
- community-led initiatives, including quality of life initiatives that address mental health and wellbeing (e.g. safe online spaces)
- free data and infrastructure investment to expand equitable, online access to health services and information
- the effective use of social media and collaboration with online health champions over developing new dedicated, but potentially less cost-effective, digital health apps.

Ensure affected communities and civil societies meaningfully participate in decisions from start to end, including the design of digital technologies and in the governance and oversight of their use in health

Raise awareness amongst citizens, and educate government officials and policymakers, on laws, regulation and governance related to human rights in the use of data and technology

Collaborate with local social entrepreneurs and social media health champions to reach young people with health information and services

Plan for and invest in the enforcement of existing data protection and digital rights policies and ensure redress for online harms.

Work with other governments and UN bodies to promote stronger regulation and accountability for social media companies

'Digital justice' requires a fundamental rethink in how digital technologies are designed, piloted and brought to scale in order to challenge structural inequalities, recognize intersectionality and center the voices of marginalized communities. Ultimately, this will produce more diverse, equitable, and accountable technologies that work for all.

6 LINKS TO FURTHER READING

Working papers that informed this study:

- o Davis SLM, Were N, Imalingat T (2021) [Digital Health Rights: Initial analysis](#)
- o Mjwana N, Imalingat T, Kpodo I, Pham T (2021) [Digital Health and Rights: Context in three countries – Ghana, Vietnam, Kenya](#)
- o Digital Health and Rights Project Consortium. (2022) Digital health and human rights of young adults in Ghana, Kenya, and Vietnam, Final Project Report
- Davis SLM & Williams C, eds. (2020) [Big data, technology, artificial intelligence and the right to health](#) (special section). Health and Human Rights Journal 22:2
- Digital Health and Rights Project Consortium (2022) [‘Towards digital justice: participatory action research in global digital health’](#), BMJ Global Health
- Privacy International (2022) [How Digital Health Apps Can Exploit Users’ Data](#)
- UNDP (2021) [Guidance on the Rights-Based and Ethical Use of Digital Technologies in HIV and Health Programmes](#)
- Y+ Global (2022) [We Matter, Value Us: A guideline for organisations on the meaningful and ethical engagement of young people living with HIV in the HIV response](#) .