

Towards digital justice: participatory action research in global digital health

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INTRODUCTION

While COVID-19 has been economically devastating for many, it has been a boon for digital health: in 2021, funding for US digital health startups soared to over \$29 million.¹ But while this growth benefits some, it is deepening existing inequalities. Big Tech in high-income countries (HIC) mines health data in low-income and middle-income countries (LMIC), creating new forms of extractive data colonialism.² The drive for more precise, granular health data risks exposing women and marginalised groups to discrimination and other harms.³ In the Global South, structural and systemic factors, such as racism, gender inequality, socioeconomic inequalities and lack of the underlying social determinants of health, affect access to smartphones, mobile data and internet, and thus health services and information. To address all these inequalities, we need new models of knowledge production that empower the public to advocate for rights-based digital governance.

How to achieve this? We have good precedent in the HIV response: for decades, community-led networks of people living with and affected by HIV have translated arcane human rights law, medicine and pharmaceutical knowledge into user-friendly, actionable language suited to local contexts.⁴ In this way, activist networks inform and mobilise marginalised groups to crack open closed global governance systems and demand a right to participate in decision-making.⁵ Peer-led networks have the opportunity to play a similar role in the digital transformation.⁶

Such community-engaged research approaches have yet to be applied widely in global health research. As one model, we present an example of a transnational participatory action research study of digital health and reflect on its implications.

DIGITAL HEALTH AND RIGHTS PROJECT

The Digital Health and Rights Project (formerly the Digital Health and Rights

SUMMARY BOX

- ⇒ The COVID-19 pandemic has accelerated the rapid growth and financialisation of digital health, benefiting private companies in high-income countries through extractive forms of data mining.
- ⇒ While a growing number of countries are now developing new digital strategies and policies to fill digital governance gaps, there is little public awareness and input into these processes of policy development.
- ⇒ New models of knowledge production are required to address these inequalities and empower marginalised groups to know their digital rights in order to advocate for rights-based digital governance.
- ⇒ The HIV response offers models for this that could be applied more widely: community-led networks of people living with and affected by HIV have translated arcane human rights law, medicine and pharmaceutical knowledge into user-friendly, actionable language, and have used this process to mobilise marginalised groups and have a meaningful say in decision-making.
- ⇒ While the 2021 United Nations Political Declaration on HIV and AIDS calls for more community-engaged research, such approaches have yet to be applied widely in global health research.
- ⇒ We present one model of a transnational participatory action research study into digital health for young adults in five countries and reflect on the benefits, challenges and wider implications of this approach.

Advisory Group) was established in 2019, partly in response to the announcement of new partnerships between leading global health agencies and Big Tech companies. The Global Fund is unique in including three permanent seats and votes on its Board for diverse civil society delegations. Thus, the study is a natural outgrowth of this public participation in high-level health governance.

Given emerging concerns about the risks posed by increased digital surveillance for marginalised and criminalised communities, three Global Fund Board delegates and an anthropologist together identified a need for more empirical data on how the digital transformation is actually experienced by



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communities.⁷ Together, we established the Digital Health and Rights Project Consortium, including the Global Network of People Living with HIV (GNP+) and its member networks, the Vietnam Network of People Living with HIV, and the National Association of People Living with HIV in Ghana; the Kenya Legal and Ethical Issues Network on HIV and AIDS (KELIN) and STOPAIDS in the UK; as well as social scientists at the Graduate Institute Geneva and the University of Oslo. With funding from Fondation Botnar, we launched the project in January 2021. BRAC University in Bangladesh and Universidad de los Andes in Colombia later joined the consortium with support from the Open Society University Network.

The study focuses on five countries—Bangladesh, Colombia, Ghana, Kenya and Vietnam—representative of five geographical regions. It investigates how young adults, ages 18–30, experience the digital transformation in health, with a focus on sexual and reproductive health, HIV and COVID-19. It explores both the empowerment potential and human rights risks of digitisation and the roles of civil society and young people in digital governance. The findings will be shared in academic articles and policy briefs and used to engage transnational youth networks in advocacy.

The 2021 United Nations (UN) Political Declaration on HIV and AIDS calls for an increase in community-led research.⁸ However, in most global health research, the civil society in the Global South are relegated to secondary roles as data enumerators, an unequal power dynamic that can shape (or mis-shape) the results.⁹ Bhakuni and Abimbola¹⁰ critique the epistemic injustice in academic global health, noting how concerns of LMIC researchers are often marginalised in favour of those of HIC researchers. This epistemic inequality is mirrored in digital health.

To address these inequalities, our consortium uses a participatory action research approach: we prioritise mentoring and support to our diverse cadre of junior researchers in universities, national associations of people living with HIV and civil society organisations in the Global South to participate in design and implementation of the study and in analysing and reflecting on the results for action. The Digital Health and Rights Project Consortium is hosted by the Graduate Institute, and an academic principal investigator ensures research methods are rigorous and consistent. A project advisory committee includes scholars, UN officials, national experts, the UN Special Rapporteur on the Right to Health and youth representatives. However, overall governance of financing, staffing, policy work, communications and partnerships is managed through consensus among consortium partners.

To conduct the study, junior researchers worked with the principal investigator to develop a shared research protocol, manual and study instruments. The transnational research team conducted comparative review of laws and policies in each country, producing jointly authored

working papers. After obtaining ethical approval in each country and undergoing ethics and methods training, researchers conduct digital ethnography in online spaces (such as social media groups), hold focus group discussions with young adults between 50 and 75 years old in each country, and interview national experts.^{11 12} As many study participants are living with HIV or have other sensitivities, the researchers use strong privacy and data security protections.

The principal investigator, postdoctoral researcher and research assistants act as coaches, hosting a weekly drop-in clinic and impromptu calls, answering questions via text message, and providing daily review and feedback on transcripts and field notes. South-South field visits among peer researchers enable collective cross-learning. A monthly consortium call also fosters collective learning, with guest lectures on digital health, artificial intelligence, digital rights and data governance.

The consortium has approved a joint publications policy and a policy on data sharing. The first scholarly publication from the project was coauthored by two of the young researchers from GNP+ and KELIN.¹³

Given the normative and financial roles in digital health in LMIC played by Global Fund, the Joint UN Programme on HIV/AIDS (UNAIDS), WHO and bilateral health aid agencies, policy engagement for this project focuses on influencing global agencies. STOPAIDS coordinates a consortium-wide advocacy plan, which gives youth and community networks a central role in engaging with, advising and promoting policy recommendations more widely. Civil society leaders in the consortium have high-level advisory and governance positions in such agencies and are regularly asked to comment on draft guidelines or to speak on the research topic in public convening. This reflects the urgent need for expertise on digital governance during a rapid transformation, as well as the expanded impact potential of a diverse consortium.

BENEFITS AND CHALLENGES OF THE PARTICIPATORY APPROACH

Scholars have documented the risks and benefits of a participatory action research approach.¹⁴ Many of these apply in our experience also.

The challenges include the time-consuming nature of collaborative work, the new skills and competencies each consortium member must master to collaborate effectively, and the risks of reproducing existing social inequalities within the consortium. Academic institutions also often struggle to facilitate partnerships with and funding to civil society.

But despite the challenges, the participatory approach deeply enriches the research. The junior researchers, most of whom are women, have been keen to highlight that young people are far from homogeneous and have different unique experiences online shaped by intersectional inequalities. They have been able to revise research questions to make local sense, have identified important

findings grounded in diverse lived experiences and have documented inspiring digital health innovations tailored to the needs of young people.

The junior researchers, with the trust of their peers, have also elicited concerning disclosures of harm: experiences of online exposure to family and community (as living with HIV, as lesbian, gay, bisexual, transgender, queer and/or questioning (LGBTQ+), as a sex worker or as a sexually active young person), risks of misinformation, censorship, cyberbullying, stalking, extortion and violence. Such harms risk further marginalising vulnerable young adults online, while contributing negatively to their mental health and well-being. The study is showing in a granular way how intersectionality and weak protection of human rights affect access to, use and design of digital health services. These insights must be addressed as health services migrate onto digital platforms.

The participatory approach also positions civil society groups with the information they need to begin addressing problems immediately, without waiting for academic publication timelines. In Kenya and Ghana, for example, the researchers saw that to young adults living under COVID-19 restrictions, digital literacy has become indispensable for participation in social and economic life. The study participants, increasingly dependent on their phones, expressed a strong need for privacy and anonymity online, but were largely unaware of their data protection rights under national laws. Immediately, civil society groups in the consortium mobilised additional funding to develop digital literacy training materials for use in their ongoing work with young people.

The collaboration is building a transnational cadre of young experts. Through their central role as codesigners, thought partners and data gatherers, the researchers are becoming equipped to authoritatively present policy recommendations in national and global fora, and in local languages, while analysing these recommendations in a global context. The project's investment in national-level capacity is crucial in beginning to redress the power inequalities created by data extractivism.

CONCLUSION

A growing literature explores participatory approaches to mathematical modelling and machine learning.¹⁵ Similarly, *The Lancet* and *Financial Times* Commission on Governing Health Futures 2030 has called for 'a governance architecture that creates trust in digital health by enfranchising patients and vulnerable groups' to promote equitable access and democratic participation.¹⁶ While states are now beginning to develop policies and strategies to fill glaring gaps in digital governance, in our observation, many such policies are developed without community input.

To avoid tokenism, such input should be grounded in sustainable community structures that ensure both representation and accountability. Young people need resources, knowledge and a level of autonomy to fully

exercise their digital rights. The HIV sector has offered rich lessons on how to build community power while elevating insights from the streets to the offices of decision-makers. Those lessons, grounded in lived experiences of discrimination, criminalisation and marginalisation, but also of transnational solidarity and empowerment, are urgently needed in the digital age.

To build the legitimacy of digital governance requires upholding the right to produce, share and benefit from knowledge. Doing this through deep community networks can give the world access to rich insights and begin to move us towards digital justice.

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