The Future of Human Rights in the Digital Age
A Multi-Country Participatory Action Research Study

Master protocol

29 September 2023

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Implementing partners

The project will be coordinated by the Principal Investigator in partnership with researchers and experts at the following institutions, members of the Digital Health and Rights Project Consortium:

- Global Network of People Living with HIV (GNP+)
  - GNP+ subgrants to and coordinates with two member networks, the Ghana Network of Persons Living with HIV (NAP+ Ghana), and Vietnam Network of People Living with HIV (VNP+),
- Kenya Legal & Ethical Issues Network on HIV and AIDS (KELIN, in Kenya),
- Privacy International (in UK),
- Restless Development (in UK),
- STOPAIDS (in UK), and
- Universidad de los Andes (Colombia).

The study is supported by Fondation Botnar from June 2023 to July, 2026, Grant REG-22-002.

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1 Background

The application of digital technologies in the delivery of health information and healthcare is increasingly gaining acceptance, and is reshaping global health, including HIV, tuberculosis (TB), and sexual and reproductive health (SRH).[1] While this transformation offers the prospect of speeding progress towards the attainment of Sustainable Development Goals (SDGs) on Health, the design, access and utilisation of digital technologies is being shaped by profound global inequalities, within and among countries. This transformation poses new threats to human rights.

In particular, the new tools of digital health, and the rise of artificial intelligence (AI), are fuelled by the collection and analysis of intrusive personal data in ways that can have lasting impacts on young people. However, young people in low- and middle-income countries (LMICs) rarely have a say in the policy decisions that shape what kinds of data are gathered about them, by whom, and how that data is used or managed.[2]

In September 2022, UN leaders affirmed that "Human rights should be at the heart of tech governance". High-level policy discussions planned for the next few years could be a turning point. We see a critical need for a robust evidence base, and for community mobilisation in low- and middle-income countries (LMICs) to inform this debate. The HIV movement has highlighted how the rights to privacy, autonomy, non-discrimination, and criminalization intersect. It is also an exemplar of a global community-led movement that has used scientific literacy to promote accountability.

The Future of Human Rights: A Multi-Country Participatory Action Research study takes the HIV movement as a site from which to explore human rights in the digital age and explore whether there are approaches that the emerging governance of digital technologies and artificial intelligence (AI) can adopt from the HIV sector. The study is part of a larger project that uses transnational participatory action research (T-PAR), training, policy impact work, and youth leadership training to support informed civic engagement in digital governance. In particular, as explained further below, the study uses a mixture of qualitative research methods to study digital literacy and empowerment; the political determinants of digital health; and meaningful youth participation, developing findings for broader application.

1.1 The Digital Health and Rights Project Consortium

The Digital Health and Rights Project Consortium (DHRP; formerly, Digital Health Rights Advisory Group) began in 2019, in response to the active promotion of digitisation by UN development agencies. We were concerned about the lack of empirical evidence on either

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[1] This protocol was adopted from Heidari, S. and Onyango, M.A., 2020, *Survival strategies and implications on sexual and reproductive health in forced displacement: A multi-country study*; Master protocol. Graduate Institute, Geneva.

[2] Wong et al, 2021. Youth engagement in digital health: a critical perspective towards meaningful youth agency in governance. MMS Bulletin 157.

risks or benefits and identified a need for more empirical data to ground evidence-based policy. With a small grant from Fondation Botnar, we launched a two-year study in Ghana, Kenya and Vietnam.

Support from Open Society University Network enabled us to add a second study in Bangladesh and Colombia, recently completed, with BRAC University (Bangladesh), and Universidad de los Andes (Colombia). We also supported the mandate of the UN Special Rapporteur on the Right to Health on her report to the UN Human Rights Council on digital technologies, innovation and the right to health published in April 2023.[3]

In the first three years of operation, the project has had significant impact on guidance and policies at UNAIDS, UNDP, the Global Fund, the new Financial Intermediary Fund for Pandemic Preparedness and Response, and recommendations to WHO's Pandemic Treaty. Our input is often sought by the UN Human Rights Office, UNDP, WHO, I-DAIR, and Transform Health Coalition. We have held briefings for embassies, UN agencies and at the Global Fund.

In June 2023, the Digital Health and Rights Project secretariat moved to the Centre for Interdisciplinary Methodologies (CIM) at University of Warwick with new resources and new personnel and launched this second phase of our work with the Future of Human Rights project.

1.2 Human rights at the crossroads

These rapid developments arise at a pivotal moment in the social and political history of the international human rights system, which is currently in a state of crisis due to numerous new challenges, including the challenge of digital transformation.

In 1948, the adoption of the Universal Declaration of Human Rights (UDHR) "reaffirms[ed] faith in fundamental human rights."[4] This set in motion a period of history in which the tenets of human rights became a key question for leading actors and institutions. With the end of the Cold War, a "culture of human rights" spread rapidly as part of global development and civil society activism.[5] By the late 1990s, UN Secretary-General Kofi Annan could proclaim that the world was living in the "Age of Human Rights".[6]

However, the early 2000s sparked a backlash. Some critics foresaw the "end times" of human rights, while others argued that growing income inequality demanded new approaches to

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[3] UN (2023). Digital innovations, technology and the right to health. Special rapporteur's report on the rights to health. Available https://www.ohchr.org/en/documents/thematic-reports/ahrc5365-digital-innovation-technologies-and-right-health.

[4] UN General Assembly. (1948). Universal Declaration of Human Rights. United Nations, 217 (III) A, Paris, Art. 1. http://www.un.org/en/universal-declaration-human-rights/

[5] Cowan J., Marie-Bénédicte Dembour, and Richard A. W, eds. (2001). *Culture and Rights: Anthropological Perspectives.* Cambridge: Cambridge University Press.; Goodale, M. "From Human Welfare to Human Rights: Considering Socioeconomic Rights through the 1947-48 UNESCO Human Rights Survey," in *Rewriting the History of Socioeconomic Rights*, eds. Charles Walton and Steven Jensen. New York: Cambridge University Press.

[6] Annan, Kofi. (2000). "The Age of Human Rights." Project Syndicate, September 26. https://www.project-syndicate.org/commentary/the-age-of-human-rights.

social justice advocacy.[7] Clarke critiques institutions as the International Criminal Court as having failed to address the lingering effects of colonialism in Africa, while Sikkink argues that deployment of rights tools and discourses has been effective in lessening abuses.[8] Critics such as Cerf[9] argue that there is no such thing as the human rights of the internet (because the internet is a means to attaining specific rights).

There are two counter trends that have emerged on the application of human rights norms beyond the human rights enforcement regime: one is the trend towards increasing campaign for the application of human rights to technology; the other is the successful use of human rights norms to advocate for global health governance reforms by HIV advocates.[10]

First, advocates' use of social media, mobile apps, drone photography and other new digital technologies demonstrate fluidity and adaptation to promote resilience in response to moments of crisis such as the Covid-19 pandemic.[11] Since people's daily lives are mostly managed online, the digital turn presents the same and sometimes more complex concerns relating to fundamental human rights issues such as freedom of expression, privacy, non-discrimination, access to information and others that are essential for full and equal participation in society.[12] Accordingly, the promotion of human rights is incomplete without the protection and promotion of people's fundamental human rights in the context of the internet and other digital technologies.[13]

Second, in the HIV sector, civil society-led HIV networks have adopted rights in the context of their advocacy and litigation for treatment access in high-income, middle-income and low-income countries.[14] More recently, this has spread to encompass key populations vulnerable to HIV, including sex workers, men who have sex with men, people who use drugs, and transgender people, who have formed national and transnational networks and who engage in health governance at institutions such as the Global Fund and UNAIDS.[15] Activists and their UN partners now similarly assert human rights of persons affected by TB.[16] Drawing on this foundation of mobilised community networks, global health advocates are both insiders and

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[7] Stephen Hopgood. 2013. *The Endtimes of Human Rights.* Ithaca: Cornell University Press.

[8] Clarke, I. (2019); Sikkink, K. (2017). *Evidence for Hope: Making Human Rights Work in the 21st Century*. Princeton, NJ: Princeton University Press.

[9] Cerf, V. G. (2012). "Opinion | Internet Access Is Not a Human Right". *The New York Times*. ISSN 0362-4331. Archived from the original on 10 March 2017. Retrieved 17 September 2023.

[10] Chua, Lynette J. (2018). *The Politics of Love in Myanmar: LGBT Mobilization and Human Rights as a Way of Life.* Stanford University Press; De Strooper, Tine and Sally Engle Merry, ed. 2018. *Human Rights Transformation in Practice.* Philadelphia, PA: University of Pennsylvania Press; Karppinen, 2017

[11] Niezen, R. (2020). *#HumanRights: The Technologies and Politics of Justice Claims in Practice.* Stanford, CA: Stanford University Press.

[12] Mathiesen, K. (2014), 'Human Rights for the Digital Age'. *Journal of Mass Media Ethics* Vol 29, No 1, pp. 2-18

[13] Karppinen, K, I. (2017). Deconstructing Digital Rights: Promises and Problems of Rights-Based Politics.

[14] Biehl, João. (2009). *Will to Live: AIDS Therapies and the Politics of Survival*. Princeton: Princeton University Press; Chan, Jennifer. 2015. *Politics in the Corridor of Dying: AIDS Activism and Global Health Governance.* Baltimore, MD: Johns Hopkins University Press; Farmer, Paul. 2005. *Pathologies of Power: Health, Human Rights, and the New War on the Poor.* Berkeley, Los Angeles and London: University of California Press.

[15] Davis, S.L.M. (2020). *The Uncounted: Politics of Data in Global Health*. Cambridge University Press.

[16] Stop TB Partnership. (2019). Declaration of the Rights of People Affected by Tuberculosis. https://www.unaids.org/en/resources/presscentre/featurestories/2019/may/20190516_tb

outsiders, advocating for accountability while receiving funding and participating in high-level policy debates.[17] Through these high-level roles and through sustained and coordinated advocacy at multiple levels, activists working in the HIV and TB sectors have successfully pushed some global health agencies to adopt human rights and gender equality commitments.[18] UN agencies working in global health have promoted human rights standards as part of their advice to countries, such as through expert and consultative mechanisms such as the Global Commission on HIV and the Law, which has developed and promoted tools for assessing and reforming the legal environment for the HIV response.[19]

The HIV experience thus offers models, tools and thinking that may be useful for global health architecture more widely. This includes a recognition of the impact of stigma, discrimination and criminalization on health service access; analysis of the components of an enabling legal and policy environment for health services; and an infrastructure of national and global communities who engage in high-level technical and political decision-making processes. [20]

At the same time, the trend towards multistakeholder initiatives as the primary form of collaboration in global governance poses new challenges. Multi Stakeholder processes offer the promise of meaningful civil society participation, improved transparency, and a way to evade the pitfalls of top-down regulation. But while some activists and scholars welcome the shift towards multi-stakeholderism to promote human rights, others have criticised multi-stakeholderism as a tokenistic process that fails to hold states accountable, creating a kind of performative consultation while in practice the private sector, bilateral overseas development assistance (ODA) funders and private foundations actually shape norms and priorities.

1.3 HIV, key populations and the digital transformation

The rapid growth of digital technologies and its impact on individual behaviour, social interactions, culture and the global economy means that an individual's capacity to attain specific level of wellbeing is unavoidably linked to contemporary digital technologies.[21] Evidently, individual rights have emerged as a constituent basis for approaching policy issues related to digital technologies and the internet.[22] While new technologies and artificial intelligence (AI), such as mobile health apps, could transform weak health systems in low-resource settings, human rights experts have highlighted real threats to privacy, equality (non-discrimination), autonomy and sovereignty. These include risks of algorithmic biases

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[17] Davis, S.L.M. (2020). *The Uncounted*.

[18] The Global Fund, "Human rights". Web page, no date. https://www.theglobalfund.org/en/human-rights/.

[19] Global Commission on HIV and the Law. (2018). *Risks, Rights and Health* Supplement. New York, UNDP, July.

[20] STOPAIDS et al (2020). HIV, Universal Health Coverage, and the future of the global health architecture: A civil society discussion paper on key trends and principles for evolution. Available at: https://stopaids.org.uk/wp-content/uploads/2020/01/HIV-Universal-Health-Coverage-and-the-future-of-the-global-health-architecture.pdf.

[21] Lupton D. (2017). *Digital health: Critical and cross-disciplinary perspectives*. London and New York: Routledge.

[22] See Karppinen, (2017).

that disfavour women and people of colour; risks of extractive regimes, or data colonialism; risks of malicious targeting due to poor data protection, and more.[23]

All these risks could have a disproportionate impact for young women, young adults living with HIV, migrants, and for criminalised “key populations” who are vulnerable to HIV (as defined by the World Health Organization [WHO], these are gay men and other men who have sex with men, sex workers, transgender people, people who use drugs, migrants and prisoners).[24] Studies have shown that key populations are at high risk of HIV infection.[25] Key populations and their sexual partners account for 47% of new HIV infections globally, and the risk of acquiring HIV is 13 times higher among female sex workers (FSWs), 23 times higher among drug users who inject and 27 times higher among men who have sex with men (MSM).[26] Moreover, transgender women are 49 times more likely to be living with HIV than other adult females and prisoners are five times more likely to be living with HIV than adults in a general population.[27]

Despite this alarming HIV burden and the progress made in global coverage of HIV testing and treatment services, key populations remain underserved[28]. Many key populations prefer to remain “uncounted” in official health studies, due to risks linked to stigma and criminalization.[29] In one example, the global network that represents sex workers cautions against mapping of “hot spots” to deliver services when this uses methods that might reveal sensitive information, inadvertently exposing sex workers to risks of violence or arrest.[30] In Kenya, national networks of key populations objected to government plans to gather

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[23] Couldry, N., Mejias, U.A. (2018). “Data colonialism: Rethinking big data’s relation to the contemporary subject”. *Television and New Media;* UN Human Rights Office. 2020. “Emerging digital technologies entrench racial inequality, UN expert warns », 15 July, https://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=26101&LangID=E; Sekalala, S., et al. (2020). “Analyzing the human rights impact of increased digital public health surveillance during the COVID-19 crisis.” *HHRJ* 22 no. 2: 1-6; Sun, N., et al. (2020). “Human rights and digital health technologies.” *HHRJ* 22 no. 2 (December): 41-48; Zuboff, S. (2019). *The Age of Surveillance Capitalism*. Profile Books; International Committee of the Red Cross (ICRC). (2018). “Digital Trails Could Endanger People Receiving Humanitarian Aid, ICRC and Privacy International Find”. Press statement, December 7. https://www.icrc.org/en/document/digital-trails-could-endanger-people-receiving-humanitarian-aid-icrc-and-privacy.

[24] Davis, SLM, Esom, K., Gustav, R., Maleche, A., Podmore, M. (2020). “A democracy deficit in digital health?” *Health and Human Rights*, January 16. https://www.hhrjournal.org/2020/01/a-democracy-deficit-in-digital-health/.

[25] Yang X et al, (2020). Social network strategy as a promising intervention to better reach key populations for promoting HIV prevention: a systematic review and meta-analysis. *Sex Transm Infect* 2020; **96**:485–491. doi:10.1136/sextrans-2019-054349 .

[26] UNAIDS. Global HIV & AIDS statistics — 2018 fact sheet. Available: https://www. unaids.org/en/resources/fact-sheet2018

[27] PreventionGapReport.UNAIDS,2016http://www.unaids.org/en/resources/documents/2016/ prevention-gap

[28] WHO, (2017). Serving the Needs of Key Populations: Case examples of innovation and good practice in HIv prevention, diagnosis, treatment and care. Geneva: Switzerland. Available at: https://apps.who.int/iris/bitstream/handle/10665/255610/9789241512534-eng.pdf

[29] Davis, SLM. (2020). *The Uncounted: Politics of data in global health.* Cambridge: Cambridge University Press.

[30] Global Network of Sex Work Projects (NSWP). (2015). “Mapping and Population Size Estimates: Proceed with Extreme Caution”. Policy brief. https://www.nswp.org/resource/mapping-and-population-size-estimates-sex-workers-proceed-extreme-caution

biometric data as part of an HIV study.[31] A new draft anti-homosexuality bill under consideration in Ghana could criminalise outreach by NGOs to gay men and other men who have sex with men, which will only increase these gaps in assessing and meeting HIV service needs.

However, a digital race among aid actors is speeding the rollout of “digital first” initiatives without consideration of the larger legal and policy environment in which these services race. UN member states, including bilateral aid agencies and implementing countries, are under pressure to progress towards the SDG 3.3 on health, and digital technologies and AI offer ways to speed progress.[32] The UN Political Declaration on Universal Health Coverage[33] is also a driver for data collection and scale-up of digital technologies. Health donors and technical agencies such as WHO, the Global Fund, and the Bill and Melinda Gates Foundation have raced to develop new digital partnerships with the private sector.[34] However, SDG 16 also commits UN member states to promote rule of law and access to justice for all, and this commitment should also be upheld in digital governance.

Increasingly, multi stakeholder platforms for digital governance seek to include youth voices: the *Lancet* and *Financial Times* Commission on Governing Health Futures 2030, the first major such exploration of digital health governance, called digital technologies the new “digital determinants” of health, and called for children and young people to be “at the centre” of future co-design of digital health solutions, participatory research and decision-making. The Internet Governance Forum includes national and regional youth initiatives that engage young people in discussions on digital governance. However, it is not yet clear to what degree such processes, and youth who participate in them, are meaningfully influencing governance decisions. Currently, there are no existing standards or norms for meaningful community participation in digital governance, and contesting definitions and norms of what digital literacy should include. Our study will help to advance this analysis and develop recommendations.

1.4 Findings from previous Digital Health and Rights Project studies

The Digital Health and Rights Project conducted a two-year transnational participatory action research study in 2021-22 of digital health and human rights of 174 young adults and 36 expert interviews in Ghana, Kenya and Vietnam. This was followed by a second study applying the same research protocol with 158 young adults in Bangladesh and Colombia. The studies

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[31] KELIN, (2017). *Everyone said no: Biometrics, HIV and Human Rights, a Kenya Case Study.* Report, https://www.kelinkenya.org/everyonesaidno/.

[32] UN Secretary-General’s High-Level Panel on Digital Cooperation. *The Age of Digital Interdependence.* 2019. https://www.un.org/en/pdfs/DigitalCooperation-report-for%20web.pdf

[33] UN Resolution adopted by the General Assembly on 10 October 2019, https://undocs.org/en/A/RES/74/2

[34] Greenwood F. (2019). “Why Humanitarians are Worried About Palantir’s New Partnership with the UN”. *Slate,* February 13. https://slate.com/technology/2019/02/palantir-un-world-food-programme-data-humanitarians.html; The Global Fund, (2019). “Private sector partners step up the fight to end AIDS, TB and Malaria”, October 9. https://www.theglobalfund.org/en/news/2019-10-09-private-sector-partners-step-up-the-fight-to-end-aids-tb-and-malaria/.

found both significant empowerment potential and significant risks in the digital transformation of health, which will inform the next stage of our work.

We found that young people increasingly rely on their mobile phones to access health information and services through Google searches, social media networks (such as Facebook, Instagram, YouTube and TikTok), and social chat groups (such as WhatsApp). A smaller number of young adults described using dedicated mHealth apps. Young people expressed enthusiasm for accessing health information through these channels, because they believed their anonymity was protected online, enabling them to avoid the stigma they had experienced in clinics. Young women said they actively seek health information for themselves, their peers and less digitally literate older relatives.

Nonetheless, the use of social media for health information offered risks as well as benefits. In particular, the studies document the rise of trusted and innovative social media health champions who offer youth- friendly information and advice, who ground their advice in medically sound sources, and create safe spaces online for discussion of sensitive topics.

Yet young people in all five countries also disclosed serious harms. These included lack of access to essential health information due to the cost of smartphones and airtime; misinformation; censorship of health information; anxiety about phone "addiction"; verbal abuse and threats; public shaming; sexual harassment and stalking; extortion and blackmail; and physical violence. These harms were especially reported by young women, LGBTQ+ people, and sex workers. Some young people also expressed anxiety about the risk of online surveillance, considering criminalization of abortion and same-sex sexual behaviour. These harms lead some young people to limit their online participation, impacting their access to health information and services.

The study found profound inequalities in access. Structural factors shaping access included gender, economic resources, rural/urban disparities, educational level, disability, sexual orientation and gender identity, religious and cultural norms, and more. For some groups, such as sex workers, these inequalities are intersectional in nature, combining to create profound exclusion, greater risks, and less access to redress.

To advance towards a more just digital future and infuse global policy and practise with new grassroots evidence and perspectives, we build on the inputs and recommendations of the previous studies. Responding to requests from study participants, we will apply a pedagogical approach in which young people are both learners and researchers into digital governance. Our objective is that young people in their diversity will become part of a broader global movement on evidence generation and advocacy for digital health and human rights.

1.5 Transnational Participatory Action Research

The use of participatory action research opens a promising and innovative approach to knowledge production and governance of human rights in technology. Because our approach engages national and transnational civil society networks, we have developed transnational platforms and decision-making processes that we propose to name Transnational PAR (T-PAR).

Anthropologists have taken a range of positions regarding human rights universality and cultural relativism in the application of human rights norms.[35] While some anthropologists favour maintaining a distance from the communities they study, other "engaged anthropologists" act as both witnesses for and champions of the rights of communities they write about.[36] However, the "engaged" approach sometimes preserves the privileged role of the anthropologist as "expert" in knowledge production. More recently, global health scholars have begun to call for new approaches to address and counter the historical legacies of colonialism in knowledge production.[37]

Participatory action research subverts the power relationships inherent in traditional knowledge production, bringing the subject of study in as a partner in design and implementation of the research project from beginning to end. Baum and colleagues describe participatory action research as an approach "based on reflection, data collection, and action that aims to improve health and reduce health inequities through involving the people who, in turn, take actions to improve their own health".[38] In this approach, participants and researchers collectively conduct research with the explicit aim of "understanding and improving" public health policy and practice.[39] As Schubotz notes, "this ethos of planning and working towards social change, rather than hoping to trigger change, sets PAR apart from other conventional types of research".[40]

While the PAR approach to research is increasingly used in evaluating public health policy at local and national levels, it is new to global health policy and governance. The transnational community networks and other infrastructure built through decades of mobilisation and financial investment in the HIV sector, and the now routinized role for civil society leaders in local, national and global governance, creates favourable conditions for trialling a PAR approach to global health policy research; and, for new and emerging governance of digital health. This study will utilise the PAR with young adults across four countries (Colombia, Ghana, Vietnam and Kenya).

In recent years, the rapid development of new technologies has opened new ways of collaboration and insight. Digital tools help PAR collaborators to communicate and share ideas even if they are not close, carrying out research in different localities. People from different countries, cultures and/or with different ways of living can now work together in a

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[35] Goodale, M. (2006). "Toward a critical anthropology of human rights." *Current Anthropology* 47.2 (June): 485-511.

[36] Billaud, J. (2016). Afterword: A Post-Human Rights Anthropology of Human Rights? PoLAR: Political and Legal Anthropology Review Online, November, https://polarjournal.org/a-post-human-rights-anthropology-of-human-rights; Speed, S. (2006). "At the Crossroads of Human Rights and Anthropology: Toward a Critically Engaged Activist Research." *American Anthropologist* 108(1):66-76.

[37] Büyüm, A.M., Kenney, C., Koris, A., Raveendran, Y. (2020). "Decolonising global health: If not now, when?" *BMJ Global Health*; **5:**e003394.

[38] Baum, F., MacDougall, C., and Smith, D. (2006). "Participatory action research." *J Epidemiol Community Health* 60:854–857. doi: 10.1136/jech.2004.028662

[39] Baum et al, (2006), Participatory Action Research.

[40] Schubotz, D. (2019). "Participatory Action Research". SAGE Research Methods, **DOI:** http://dx.doi.org/10.4135/9781526421036840298 |

project (Cahill, 2007). This creates the potential for more diverse and inclusive research participants, producing a wider range of perspectives and experiences.

We thus propose T-PAR as an inclusive research approach that emphasises community-led engagement and empowerment across diverse national contexts, resulting in policy engagement at both local and transnational levels of decision-making. Multi-country PAR involves conducting research across several countries, primarily for comparative analysis among distinct national contexts (Basch et al., 1993; Kindon et al., 2007). By contrast, we argue that transnational PAR builds on collaborative engagements that study and address issues spanning national borders, and that engage in policy and decision-making in global governance spaces. Crucially, we believe that TPAR should include representation from the community under study not only in local research, but also in the leadership team that coordinates the transnational study. In the case of our project, this leadership role is played by national human rights groups and national and global networks of people living with HIV, who occupy leadership roles in the governing steering committee of our project.

The Future of Human Rights project is governed by a Steering Committee, made up of representatives from each organisation in the consortium (University of Warwick, GNP+, KELIN, Privacy International, Restless Development, STOPAIDS, and Universidad de los Andes). In addition, each of four national Community Advisory Teams from the study countries will elect a representative to the Steering Committee, two of whom will be young adults. The Steering Committee meets monthly to manage strategic decisions for the consortium, and these meetings are complemented by quarterly meetings of the full consortium to discuss updates on work plans, with an annual in-person meeting in a different location each year (Nairobi, Cape Town and Geneva).

Given that participatory action research study actively engages all relevant parties (participants, communities, and others with interest in the issue being studied) in defining the research problems, developing questions, gathering data, analysing the collected data, and preparing recommendations for advocacy and action; drafts will be created by the PI and postdoctoral researcher, and shared with the civil society partners for review and comment before finalisation. The partners meet weekly in a research clinic to discuss progress on the stages of the research project. These weekly meetings offer the opportunities for consortium members to hold discussions across national boundaries on:

- The research project objectives and questions
- Human rights standards and concepts relevant to digital health
- Specific questions and issues in each of the four countries
- Ethics of research, safety, confidentiality, and respect
- Risks and mitigation measures
- Writing field notes, tracking interviews and recordings
- Research methods exchanges and skills-sharing.

The T-PAR approach will undergo an independent evaluation in year three of the project, generating learning for wider dissemination.

2 Research questions

Our study will investigate the following three areas (see Table 1, *Areas of inquiry, questions and methods)*:

1. **Digital literacy and empowerment**
2. **Political determinants of digital health: Laws and policies from the ground up**
3. **Meaningful youth participation in digital governance**

Within these three areas of inquiry, we will investigate these cross-cutting questions:

- What is the future of human rights in the digital world, and what role can diverse grassroots communities in LMICs play in shaping that future?
    - What kinds of digital literacy and empowerment do young people and communities need and want?
    - How do young people experience multiple digital divides (e.g. gender, race, sexual orientation, nationality, language, socio- economic class, and geography, among other factors) as intersecting to shape their empowerment or disempowerment?
    - How do populations who are criminalised and stigmatised (including LGBTQ+ people, sex workers, migrants) experience the risks and realities of state surveillance in the digital transformation?
    - What lessons can be learned from the HIV movement as a case study to inform future thinking, mobilisation and advocacy that promotes human rights in digital technologies?
    - What is the right to meaningful community participation in digital governance? How can diverse actors collaborate, nationally and globally, to promote fulfilment of human rights in the use of data and digital technologies?

Table 1: Areas of inquiry, questions and methods

Area of inquiry	Research questions	Research methods	Numbers of participants
What is the future of human rights in the digital world, and what role can diverse grassroots communities in LMICs play in shaping that future?		• Findings from all three areas of inquiry below. • Independent evaluation of T-PAR approach in year 3	**Between 200-400 participants**, as outlined below:

Digital empowerment	What kinds of digital literacy and empowerment do young people and communities need and want?	● Narrative review ● Focus group discussions ● Pre-and post-training assessments	Approx. 20 participants in each country -- Total of **80 participants**
Political determinants of digital health	How do young people experience multiple digital divides (e.g. gender, race, sexual orientation, nationality, language, socio- economic class, and geography, among other factors) as intersecting to shape their empowerment or disempowerment?	● Desk review of laws and policies ● Digital ethnography ● Focus group discussions (incl. Photo Voice) ● Key informant interviews	240 focus group discussions (8 participants each) in rural, urban and periurban settings, in each country Approx. 10-12 key informant interviews in each country **Total of 190-200 participants**
	How do populations who are criminalised and stigmatised (including LGBTQ+ people, sex workers, migrants) experience the risks and realities of state surveillance in the digital transformation?		
Meaningful youth participation	What lessons can be learned from the HIV movement as a case study to inform future thinking, mobilisation and advocacy that promotes human rights in digital technologies?	● Field observation: diaries, field notes, blogs ● Key informant interviews	10-15 participants in each country **Total of 40-60 participants**
	What is the right to meaningful community participation in digital governance? How can diverse actors collaborate, nationally and globally, to promote fulfilment of human rights in the use of data and digital technologies?		

The methods are discussed in more detail in section 5, below.

3 Conceptual framework

Our theoretical grounding for this research project is based on the results of the previous studies we conducted in Colombia, Ghana, Kenya and Vietnam, as well as review of current scholarship on law, policy and governance of digital health.

Building on the work of the Lancet and Financial Times Commission, referenced above, a growing number of global health scholars such as Jahnel and colleagues[41] have argued that health inequities depend on "digital determinants", such as limited access to digital tools, lack of high-quality data, or digital tools that fail to meet the specific needs of target populations. Building on widely accepted models of socioecological determinants of health equity, they identify digital entry points for research and intervention.

However, the "digital determinants" approach risks granting digital technologies too much agency, while masking responsibility within a broader environment that creates these inequities. By contrast, Storeng and colleagues[42] identify some ways that political determinants shape health inequalities – in particular, finance, governance and power, often expressed by laws and policies or gaps in governance that create a lack of accountability for powerful private actors.

Such governance should not be understood as only including digital and AI governance, but as extending to a broader environment of laws and policies shaping inequalities for women and marginalised groups. Given our collective grounding in the history of the HIV response, this study's analysis is informed by work done by the Global Commission on HIV and the Law,[43] UNAIDS and others who have drawn on decades of research and consultations to define the legal, human rights, and gender-related barriers that can create either an enabling or a hostile environment for HIV services. They recommend these barriers be addressed through support for know-your-rights training for communities, as well as advocacy, litigation and civic engagement to promote law and policy reforms. Likewise, Sun and colleagues have identified relevant standards in the adoption of digital health technologies such as the rights to health, non-discrimination, benefit from scientific progress, and privacy.[44]

Our conceptual framework thus builds on the digital determinants of health framing by adding a critical analysis of political determinants, extending to intersecting laws and policies. We will investigate how the lived experience of young adults in their diversity with digital technologies is shaped by this broader regulatory environment, and how they might begin to change digital governance through civic engagement.

Here, we are led by the body of work launched by Sally Engle Merry's (2006) work on the use of ethnographic research to understand how rights are "vernacularized" or translated into local contexts, through dynamic and iterative interpretative practices. Merry (2018) argued, "the focus on how human rights travel and how they are transformed offers an invaluable

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[41] Jahnel T, Dassow HH, Gerhardus A, Schüz B. (2022). The digital rainbow: Digital determinants of health inequities. *Digit Health*. Oct 2;8:20552076221129093. doi: 10.1177/20552076221129093.

[42] Storeng KT, Fukuda-Parr S, Mahajan M, Venkatapuram S. (2021). Digital technology and the political determinants of health inequities: Special issue introduction. *Global Policy.* 05 August: https://doi.org/10.1111/1758-5899.13001.

[43] Global Commission on HIV and the Law. (2018). *Risks, rights and health: Supplement.* Available: https://hivlawcommission.org/supplement/.

[44] Sun, N., Esom, K., Dhaliwal, M., Amon, J.J. (2020). Human rights and digital health technologies. *Health and Human Rights Journal* 22(2), 21-32.

corrective to those perspectives locating human rights only in formal institutions and laws."[45] Human rights, she argued, is flexible enough to be "reinterpreted and redefined in a variety of contexts and for a broad range of problems."

4 Project overall

The project will conduct qualitative research with between 200-400 participants in Colombia, Ghana, Kenya, and Vietnam, using a transnational participatory action research approach which sets the research agenda from the community level. The resulting evidence will be analysed together with Community Advisory Teams in each country, and by a global Digital Rights Community of Practice.

For context: the research is one part of a larger project. In years 2-3 of the project, members of the consortium (GNP+ and Universidad de los Andes) will develop and deliver digital literacy training for young adults in all four countries. Warwick will establish an open-access Digital Literacy Hub sharing self-paced training materials (both our own, and other organisations') for wider use. Coordinated by STOPAIDS and Privacy International, community-led national policy work will be complemented by global policy work, using the findings from both the previous studies and the new study to participate in digital governance discussions and processes. Restless Development will support youth leadership across the consortium, working with young adults from the Community Advisory Teams to support their participation in national and global youth consultations on digital governance. The research process will inform and infuse these other work streams.

5 Research plan, sites and timeline

The study will take place from December 2023-June 2026 and will include desk research to analyse laws, policies and related gaps; qualitative research in Kenya, Ghana, Vietnam and Colombia with young adults; and participant observation with young adults who participate in digital governance discussions on national and global platforms. Following the above-mentioned transnational participatory action research (T-PAR) approach, a Community Advisory Team in each country will facilitate participants in the research to participate in developing plans and tools collaboratively, collaborating on implementing the research, participating in training, and reflecting collectively on the results, using them to make policy recommendations.

We plan to focus on Kenya, Ghana, Vietnam and Colombia, where we did our first two studies. The countries were identified by the consortium member organisations based on interest by the national institutions to participate in the study. The countries also helpfully represent four different geographic regions from the global south (Latin America, West Africa, East Africa and Southeast Asia) that all have significant youth populations, and that represent different stages of digitization.

We plan to follow these stages in conducting the research:

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[45] Merry, S.E. (2018). Preface, in Merry and DeStrooper, T., eds. *Human rights transformation in practice.* Philadelphia: University of Pennsylvania Press, p. ix.

1. **Ethical Review** - The research team at the University of Warwick is submitting the research protocol to the Humanities and Social Sciences Ethics and Research Committee (HSSERC) at the University of Warwick for approval. The national organisations (KELIN Kenya, NAP+ Ghana, Universidad de los Andes, and VNP+) will also apply for ethical approval in each study country. The aim is to share Warwick's approved protocol with the national Principal Investigators for guidance in their process to secure ethical approval within their countries. Given that we have successfully obtained this approval in all four countries in the previous study, we do not envisage any challenges. The PI and the Post-doctoral Research Fellow will coordinate an online training for national partners from Kenya, Ghana, Vietnam and Colombia on ethics and methods of field research, as part of the field training in November, 2023. The training will include review and discussion of data collection tools for each country.

2. **Establishment of Community Advisory Teams** – In each of the study countries, the national organisation (KELIN Kenya, NAP+ Ghana, Universidad de los Andes, and VNP+) is establishing a national Community Advisory Team (CAT) made up of 12-14 representatives of civil society organisations working on health and human rights, including young people who participated in the previous phase of the project. Each national CAT reviews and provides advice on the research focus and plans, reviews and advice on tools and instrument used in the research, participates in recruitment of participants and analysis of the research findings, and participation in national validation meetings. Given that input from each CAT will be diverse, final decisions about the research plans are made by the national organisation in collaboration with the Principal Investigator at Warwick, to ensure commensurability and coherence across the multi-country study.

   The CAT members will receive training in human rights and youth leadership delivered by Restless Development, an NGO in the consortium. Each CAT is chaired by a young staff from the national organisation, and assisted by a vice-chair from among their members. The vice-chair will also join the Steering Committee which governs the project, and receive additional support from Restless Development to brief and debrief before and after each Steering Committee meeting. This approach ensures a direct voice from study participants and affected communities in overall governance of the project.

   CAT members will also draw on the findings from the previous studies and the results of the desk review (described below) to identify a major focus of their policy impact work. Potential examples include Kenya’s proposed eHealth bill, or Ghana’s planned Digital Health Strategy. The CAT members will develop plans to engage with these processes in their own country through consultations, blogs, letter-writing and direct engagement with officials to share policy recommendations. The UN Development Programme will convene meetings in Ghana and Kenya to support these discussions, drawing on their own published normative guidance on ethics and human rights in digital technologies for health.

   STOPAIDS and Privacy International will coordinate policy work across the consortium, including engagement with and formal submissions to UN and regional human rights mechanisms, and presentations at UN and other international convenings on digital governance, such as those related to development of the Global Digital Compact or convened by the Internet Governance Forum.

3. **Validation of focus group discussion and interview guides** – The Warwick team will draft focus group discussion and interview guides for review and input by the other research teams. In keeping with the participatory action research approach, each national research team will also share the tools with their national CATs for input. All inputs will be reviewed by the PI and postdoctoral researcher, who will finalise instruments for consistency across the four countries.

4. **Desk review: Laws and policies in study countries -** Once approval is received from Warwick, the consortium will begin the synthesis of three inception papers that emerged from their previous study with the aim of completing this process in December, 2023. The synthesised paper will form the basis for a comparative review of laws and policies in each country relevant to the study (e.g. laws and policies that criminalise key populations' behaviours; or address digital health, data protection, artificial intelligence regulation, or ICT), identifying policy processes where the research findings could contribute to impact. The desk review will be used to draft country briefing papers for each country that can inform the study and also be used by civil society groups to inform briefings for government agencies and funders of digital health interventions. Subsequently, a narrative review of literature on digital literacy will be undertaken in the first quarter of 2024.

5. **Field research** takes place in Colombia, Ghana, Kenya and Vietnam from January to September 2024, staggering the data collection across the four countries. This will aim to gather qualitative data on the research focused areas for each country. The team at Warwick will work with researchers from consortium members participating initially, and gradually shifting to consortium staff taking the lead in interviews. We will aim to engage a total of 200-400 participants across all four countries.

   In each country, research will include a total of 6 focus group discussions, including 2 FGDs each (8 participants per FGD) in rural, urban and/or peri-urban regions.

   We will hold approximately 60 key informant interviews across all four countries (15 in each country) with a mix of civil society and community leaders, government officials, human rights experts, UN officials, and private sector leaders to provide insights into the research questions.

   Firstly, the fieldwork will begin in Kenya in January 2024 for approximately four weeks. As indicated earlier, the team at Warwick aims to support the Kenya Team by working with their researchers initially and gradually handing over to the country research team for completion. If resources and travel restrictions permit, researchers from Ghana, Vietnam and Colombia may participate in the research in Kenya to observe and provide support.

   Subsequently, the research shifted to Ghana in March 2024 by following the same four-week model used in Kenya, with Warwick researchers leading initially and NAP+ Ghana gradually taking the lead with support and guidance from the PI and postdoctoral researcher. Field research exchanges may occur with other national researchers participating from Kenya, Vietnam and/or Colombia.

In June, 2024, the research continues over a four-week period in Hanoi, Vietnam, following the same model as utilised in Kenya and Ghana, with the team from Warwick initiating and the national VNP+ network staff gradually taking the lead.

Finally, field work for the research will conclude in Colombia in September, 2024. The team at Universidad de los Andes will gather qualitative data in Colombia within a period of four weeks in consultation with the team at Warwick.

6. **Data analysis** – Once data collection is complete, researchers will conduct thematic analysis using Dedoose, an online platform, and code a group of sample transcripts inductively, drawing on themes identified in the literature review. The full consortium will finalise the draft codebook. Some young researchers on the CAT will be trained in thematic analysis. Each transcript will be analysed by two coders.

7. **Validation** - As we did during our prior studies, national researchers will present the draft findings and recommendations to study respondents in an anonymous online video conference in each country, solicit feedback, and discuss next steps. The research teams will finalise the analysis in its annual meeting.

8. **Digital Rights Community of Practice -** As research will be conducted iteratively with policy advocacy, analysis of case studies will benefit from a broader conversation with human rights scholars and practitioners from the study countries and from international organisations. In years two and three of the project, the Community of Practice will meet quarterly to discuss the research case studies and analyse how to apply human rights standards in practice. Participants in the Community of Practice will be invited from among leading digital rights scholars and advocates; attendees at the consultations and dissemination meetings of the UN Special Rapporteur's report during 2022-24; and from related convening and discussions to develop a Global Digital Compact. They will be invited to consider how human rights norms and standards should have been applied to specific case studies, and to develop recommendations.

6 Research methods

The project will combine qualitative methods strategy from research traditions in Sociology and Anthropology, as well as legal and policy analytical tools. This is in line with the interdisciplinary nature of the project. In doing this, the project will utilise a transnational participatory action research approach, in which members of the study population are engaged in developing research plans, design of the study, implementation, analysis and reporting.[46]

6.1 Law and Policy Review

The project will begin with review of the legal and policy environment in each of the four countries. As a first step, we will update and synthesise earlier desk reviews published by the

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[46] Baum F, MacDougall C, Smith D (2006). Participatory action research. *Journal of Epidemiology & Community Health*; **60:**854-857.

project on the legal and political context of digitalization[47]to create a baseline upon which this study's rationale will be built. The papers in question reviewed digital health and human rights literature and studies at the global level, as well as the legal, policy and normative context of Kenya and Ghana: including primary research within the studies context.

This research synthesis will be led by the PI and postdoctoral researcher in close collaboration with researchers at the four national organisations in Colombia, Ghana, Kenya and Vietnam. The research synthesis will enable an iterative discussion between initial research findings, gaps and potential areas for further exploration in this multi-country study. In addition to the research synthesis, the team at Warwick will undertake a narrative review on digital literacy in collaboration with researchers from our consortium partners in Colombia.

6.2 Digital Ethnography

Digital ethnography will take place from January 2024. This method uses observation in digital spaces to study the relationships, social behaviours, and cultural practices made possible by social media, community forums, blogs, e-commerce, and other online fora. Virtual spaces in which online ethnographies have been carried out include Facebook groups, Reddit threads, message forums, Twitch streams, and blogs. In this project, digital ethnography will mainly be conducted as a way of surfacing contextual information about the concerns that community members have around digital health technologies and AI, and to better understand how these are discussed in digital spaces in each of the focus countries.

The digital ethnography will be carried out by national organisations with support and advice from the PI and postdoctoral researcher as part of the PAR approach. This will allow the project to (i) collect contextual information which can be further investigated using other ethnographic research methods; (ii) recruit participants for focus group discussions and key informant interviews; and (iii) create a direct link to participation as part of PAR research. At a later stage, we will return to the digital spaces to validate our findings and recommendations (i.e. share for comment and input).

During the law and policy review, the research team will work with the partners to identify digital spaces appropriate for research in each country, selecting those with the most relevant discussions, and highest levels of engagement, judging by quantity of followers and posts.

6.3 Semi-structured key informant interviews

The project will utilise semi-structured one-to-one interviews with experts and community leaders who offer specialised expertise relevant to one or more of the study focus areas. The PI, postdoctoral research fellow, and researchers in the national organisations will develop a list of potential interviewees, aiming for consistency across all four countries. These will be individuals who have demonstrated interest in governance of digital health at national or global levels, and could include UN officials, government officials, academic experts,

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[47] DHRPC (2022). Digital health and human rights of young adults in Ghana, Kenya, and Vietnam: final project report. Available at: https://repository.graduateinstitute.ch/record/300591?_ga=2.99187678.1735834843.1682602161-345088509.1672743223

community leaders, and experts at international organisations, private enterprises or civil society organisations.

The purpose of the study will be explained in the recruitment process, and participants will be encouraged to raise any questions or concerns before the interview. After a brief introduction to the study, the interviewer will obtain signed informed consent from the key informant. Where political contexts may make this difficult, we will obtain verbal consent and this will be audio-taped.

Trained staff will conduct all interviews using an interview guide; however, interviews with key informants will be semi-structured and open-ended, allowing for detailed and in-depth discussions of issues. The interview guide will aim to elicit information on views on the research questions chosen by each country. Information collected through key informant interviews will be exploratory in nature (e.g., insights into digital literacy, concerns relevant to digital governance, observations on meaningful youth participation).

By utilising this semi-structured method, we open up a more open and interpretative framework which can enable spontaneous, less structured interactions between researcher and participant; and which might also allow participants to take on a more active role in directing the agenda and the generation of research knowledge. This method is well-suited for a participatory action research project in which civil society participates in research design and implementation.

6.4 Field observations

Field observations will complement semi-structured interview data and FGDs as it will provide much depth and understanding to the responses provided by participants during the field work. In particular, we aim to use field observation as a methodology for young participants on the CATs as they engage in government, UN and other multi stakeholder digital governance consultations. Through diaries and blogs, participants will be invited to document their journeys as emerging youth leaders, and to reflect on the experiences they have with participation in digital governance, identifying what they define as constituting “meaningful” participation as opposed to tokenistic youth consultations.

Additionally, observations will also be utilised to triangulate emerging findings; that is, they will be used in combination with qualitative data and the updated inception papers.[48] Some national researchers will undertake daily observations at the study areas using a semi-structured observational template.

6.5 Focus Group Discussions

Focus group discussions (FGD) are semi-structured interviews conducted with several individuals at a time, under the direction of a moderator.[49] This interview format can provide

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[48] Merriam, S.B. and Tisdell, E.J. (2016). Qualitative Research: A Guide to Design and Implementation (4th ed.). San Francisco: John Wiley & Sons, Inc.

[49] Kreuger RA and Casey MA. *Focus groups: A practical guide for applied research*. 3rd edition. Thousand Oaks, CA: Sage Pubications, 2000.

quick information about general topics of interest or specific information on issues about which little is known. Information collected through these focus groups may be used to validate findings from other individual interviews that were raised by key informants, or observed in digital ethnography or in participant observation.

The strength of this research method is its focus on generating data based on everyday discourse taking shape at the level of the group. A weakness of the methodology is that it is very sensitive to group dynamics. This means that certain participants might come to dominate the discussion; or that certain topics will come to be dominant while others might be relegated to the margins, based on the interest of a few in the group. It also has the embedded weakness that the focus group might become driven by a form of 'majority rule' wherein a minority in the focus group might not want to, or feel comfortable to, express their opinions. Some participants might be reluctant to speak freely on topics considered to be taboo or stigmatising, or those that are subject to criminalization. They may also feel reluctant to speak on topics that they suspect may embarrass others, or that could put their country or their community in a bad light. For all these reasons, the participation of sensitive and experienced local partners as focus group guides will be important to create a safe atmosphere.

Participants in focus groups will be recruited from three study sites (Rural, Peri-Urban and Urban) in each of the four study countries using purposeful sampling techniques and snowball sampling methods with the help of the CATs. Researchers will answer their questions, address concerns, and tentative consent will be obtained informally at the recruitment stage.

During the focus group discussion, after a brief introduction to the study, the moderator will obtain formalised verbal informed consent from each participant, separately, and this will be recorded and witnessed (see Section 6.4 below). The objectives of the session will be outlined with the aid of the focus group guide, who will be a partner from the local organisation, and the session will proceed. Focus groups will be conducted by a primary interviewer and a note taker, with the aid of the focus group guides to elicit individual responses. The interviewer will aim to elicit discussion on issues related to behaviour, socio-demographic characteristics, acceptability of digital health technologies, questions or concerns about everyday uses of technologies, and access to healthcare services.

At the end of each FGD, the researchers will transform their handwritten notes into electronic FGD notes. FGD notes may be written in the language in which the FGDs occurred, but before submitting them as part of the FGD report they will be translated into English. Participants will be invited to choose their own pseudonyms for use during the FGDs. The pseudonym and the associated ID number for each FGD participant will be used consistently in all FGD notes and computer-based records. For cross-country comparison, a unique number will be assigned to each FGD participant (e.g., ACCRA–FGD1–M1 / HANOI–FGD3–F5). The legal names of individuals will not be noted at any time, i.e., all recorded and written records will only display the participant numbers, and not individual names.

6.5.2 FGD eligibility and sampling methods

In the ethnographic research in the country, we will use purposive sampling and snowball sampling techniques to recruit participants for key informant interviews and focus group discussions through the national organisations and the CATs. We will aim to interview a total of 190 participants approximately across all four countries.

Participants will be young adults (ages 18-30) engaged in or well-informed about the usage of (or non-usage, or hesitancy about using) mobile phones and online sources in seeking or sharing information about, or accessing, HIV, TB, sexual and reproductive health (SRH) services. These may include mHealth apps used to obtain health information, to influence risk behaviours, to enable patients to communicate with medical personnel (e.g. to schedule health care appointments or ask questions), or other health care interventions.

Participants may be openly living with HIV or may be from populations that are vulnerable to HIV, also known as “key populations” (young women, gay men and other men who have sex with men, transgender women, sex workers, people who use drugs, or migrants). Given the sensitivities related to HIV status and criminalization of some of these behaviours in the study countries, we will be especially diligent to safeguard participants’ security, safety and anonymity.

Purposive sampling technique is a type of non-probability sampling in which participants are purposely invited because of their knowledge or experience related to the topic under study.[50] As noted above, we and our national partner organisations have established partnerships with numerous local organisations in each country who are either led by people living with HIV, or work closely with communities living with and affected by HIV, and who provide direct services for key populations. The participants will be purposely selected in collaboration with the partner organisations.

We will combine purposive sampling methods with a snowball sampling methodology. Snowball sampling yields a study sample through referrals made among people who introduce individuals with similar characteristics to those under study.

In Kenya, research will be conducted in Swahili and English, and in English and any other appropriate local language in Ghana. In Vietnam, research will be conducted in Vietnamese while the study in Colombia will be conducted in Spanish. Any interpretation will be provided by individuals who work for or are close to the national organisations, and who have the trust of the community participants.

6.6 Mentoring and debriefing researchers

An initial training for all national researchers in ethics, methods and data management will be held online in November 2023, with additional training in person during field work. A field research manual has been drafted based on the previous study and will be reviewed and updated for this project.

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[50] See Merriam & Tisdell, (2016). Ibid Note 48

During the full three-year period of the grant, the PI and postdoctoral researcher will hold weekly video conference calls ("research clinics") to debrief with national staff engaged in research and will remain in close contact between these calls through secure encrypted text messages. Either the PI, the postdoctoral researcher or both will travel to each country to participate in the initial phase of data-gathering. In addition, some researchers from national organisations will travel for field study exchanges to support peers in other countries and learn from peer experiences.

During the in-country field research, the researchers will hold daily debriefing sessions with the national staff, complemented by monthly meetings with senior managers at each national organisation.

The purpose of the debriefing meetings are:

- For national staff to update each other on progress with data collection,
- For the researchers and national staff to discuss key findings from data collection so far, including differences and similarities,
- For field staff to discuss any problems/changes with the tools and instruments, or any emerging problems with the study,
- To provide a forum for the field workers to express concerns, raise any safety/security issues or other ethical concerns that need immediate attention, and
- To provide peer to peer learning for field workers.

6.7 Informed consent

In face-to-face interviews, such as key informant interviews and focus group discussions, we will obtain signed informed consent, but will offer the option of witnessed verbal informed consent to those who may be reluctant to sign their names (for instance, those who are living with HIV or members of criminalised groups such as LGBTQ+ in some countries). For those populations, written consent may cause psychological discomfort, if they worry that signing a form may expose their identities to others. In the previous phase of the study, only a tiny minority of participants opted for verbal informed consent.

Our informed consent process for both key informant interviews and focus group discussions involves three steps: 1) Provision of a comprehensive verbal description about the study and participant's rights in layman's terms; 2) An explanation of what is being asked of the potential participant, and opportunity to ask questions or request modifications to the interview process; and 3) Requesting and obtaining potential participants' consent, clarifying that the participant fully understands, is competent to consent and is freely participating in the research.

Participants will be able to withdraw from the project at any time during the research process, and to request deletion of the information they have previously provided. Participants will also be offered the option to use a pseudonym of their own choosing, if they prefer.

For those few who opt to provide verbal consent, the consent will be witnessed, and audio recorded. The witness will be an independent person not part of the research team.

Digital ethnography is an emerging methodology, and as such, norms around what is considered public or private are similarly still emerging. The literature on ethics of informed consent in digital ethnography is divided, and currently there is no clear consensus, given that many digital spaces have a mix between public and private groups and communications. Murthy argues that open forums or communities should be considered as public spaces where unmediated data collection should be allowed.[51] Others have argued that researchers should always clearly identify themselves as such, in any setting.[52] Analysis of the application of GDPR to ethnography by the Spanish National Research Council concludes that "ethnography is sometimes irreducible to consent".[53] To obtain informed consent in digital ethnography for this project, we thus propose a two-tiered approach.

First, on platforms which are considered public (such as public Facebook groups and Twitter) the project will treat such spaces as public domains. The project will not quote or reproduce any data that might be identifiable from such public digital spaces.

Second, in any digital space where access is restricted and given only by moderators or group administrators (such as an instant messaging group, or a closed Facebook group), informed consent will be sought in writing from the group moderator/administrator. On being added to the group by the administrator/moderator, the researcher will inform the group in writing about the research project and its purposes, affirming that no identifiable data will be utilised, and requesting individuals to contact the researcher directly if they wish to be excluded from the study.

In public settings of everyday life, obtaining written informed consent to conduct participant observation is generally not required for the following reasons:

1. Ethnographic research does not involve a diagnostic, therapeutic or clinical intervention, nor does it involve invasive questioning about the personal lives of informants.
2. Ethnographic research occurs in settings of everyday life and social interactions, where participants are free to walk away or refuse to engage in a conversation or answer any question. Consent must be ongoing and active for research to occur.
3. The research involves no more risk to participants than they incur in living everyday life and in their routine use of digital spaces to connect with friends, colleagues and others.
4. The lack of written informed consent will not affect the welfare of the participants, which remains the utmost priority throughout the research.

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[51] Murthy, D. (2008). "Digital ethnography: An examination of the use of new technologies for social research." *Sociology,* 42(5), 837-855.

[52] Bruckman, A. (2002). Studying the amateur artist: A perspective on disguising data collected in human subjects research on the Internet. *Ethics and Information Technology*, *4*(3), 217-231; Bruckman, A., Luther, K., & Fiesler, C. (2015). When should we use real names in published accounts of internet research. *Digital research confidential: The secrets of studying behavior online*, 243.

[53] Jimenez, AC. (2018). "A data governance framework for ethnography v. 1.0". https://digital.csic.es/bitstream/10261/172227/3/data%20governance%20framework%20181115.pdf.

5. Obtaining written informed consent is impossible or impracticable to carry out the research given the ethnographic research design, i.e., digital ethnography.

For this reason, on platforms which are considered public spaces used in everyday life (such as in public social media spaces, such as Facebook and Twitter) the project will treat such spaces as public domains. The project will not quote or reproduce any identifiable data from public sites.

In closed digital spaces (such as instant messaging groups) where there is a reasonable expectation of privacy, the project proposes a more specific approach, detailed below in section 6.4.

7 Data management and analysis

7.1 Data management plan

Notes will be recorded using word processing software (MS Word). Audio recordings will be recorded using mobile phones or videoconference software in mp3 format. Additional data gathered by researchers will include screen grabs of websites, transcriptions of audio recordings, photographs, and brochures or PDFs obtained by field researchers. These will be treated as Restricted data under University of Warwick's data management guidance and will be sent to the postdoctoral researcher using encrypted software (SwissTransfer). He will upload data to a SharePoint drive which is accessed only by the PI, the postdoctoral researcher, and a research assistant.

A copy of all original transcripts will be stored in encrypted folders at the offices of the four national organisations. Original paper-based notes will be kept in secure locked cabinets at the national offices. Access to data will be limited to the PI and research staff. We expect the data to be under 20 GB, mostly dedicated to the audio recordings.

The postdoctoral researcher will be responsible for uploading, indexing and managing data, including all codes. Continuous quality checks will be performed by the PI to ensure that code numbers are recorded properly for each participant. Folders will be created to sort documents based on subjects following a directory tree. Merging of data sources will be conducted under the supervision of the PI. All databases and storage accounts will be password protected, and data will be encrypted before transmission over public networks.

The data will be accompanied by the following contextual documentation:

1. A spreadsheet document detailing the contents of any handwritten notebooks (table of contents with date, place, people, and subjects).
2. Text files which detail the archives used and access conditions to the data.

It will be the responsibility of:

- Each researcher to annotate data with metadata,

- the Principal Investigator to check weekly (during the field research, monthly otherwise) with all participants to assure data is being properly processed, documented, and stored.

All interviews and FGDs will be translated into English and transcribed, as soon as possible. Translators will be familiar with the conceptual framework of the research and its objectives, and in any questions that arise about interpretation, translators will be encouraged to communicate directly with the PI.

A standardised layout shall be applied to all transcripts to facilitate the comparison of data at the analysis stage. The transcription will be proofread against the audio file by both the national researcher and by a member of the research team at Warwick to check for accuracy, identify any missed or misheard words, ensure transcripts are fully anonymized, and to clarify any areas of confusion or unclear terminology. An agreed cleaned version of the transcription will be created, ready for translation into English.

7.2 Data access and security

The project respects all the constraints and requirements as laid down in the General Data Protection Regulation (GDPR) and supervised by the Humanities and Social Sciences Research Ethics Committee (HSSREC) at the University of Warwick. Generally, data will be gathered in accordance with the GDPR principles of data minimization, pseudonymization/anonymization, transparency, fairness, encryption, data handling and usage. The processes for adhering to these standards have been duly described in some of the sections above. Additionally, further details on how field data will be handled has been provided below.

Interview notes and focus group notes will not contain identifiable information, only an unidentifiable unique sequential code, and a unique site identification code. Access to data will be limited to the research staff and investigators. Any person having a copy of the database will have to sign a data use/sharing agreement as stipulated by GDPR. Sensitive data transfers will be end-to-end encrypted.

All data collected outside the United Kingdom crosses borders electronically and is stored directly on the dedicated SharePoint for the project.

7.3 Data storage

The secured shared drive at CIM, University Warwick where all data is centralised is regularly backed-up with minimal risk of data loss. This is in addition to the data stored securely with consortium partners in adherence to the principles of GDPR standards at the University of Warwick.

<u>Fieldnotes:</u> Fieldnotes will be stored for a minimum of 3 years beyond the award period. Since the data are sensitive, they will be stored in encrypted external hard drives and destroyed after the 3 year period.

Interview data: Audio data will be stored for a minimum of 3 years beyond the award period. Since the data are sensitive, they will be stored in encrypted external hard drives and destroyed after the 3 year period. The PI is responsible for this task. For anonymized interview transcripts, we will preserve the data for a minimum of 10 years on an open repository. Printed transcripts during the process of data processing and analysis will be shredded.

8 Ethics, risks and benefits

8.1 Ethical issues, risks, and mitigation measures

Working with people living with HIV and key populations, as well as working with civil society groups in politically restrictive states, comes with risks that could potentially affect participant wellbeing. Young adults in this study include some whose identities are stigmatized or marginalized in the countries under study, including HIV status and potential engagement by some participants in behaviours that may be criminalized in the country.[54] This study does not involve experimental or invasive intervention of any nature. However, preliminary risk analysis indicates that study participants may experience possible political risks, social risks or inconveniences.

Our consortium partners have extensive experience providing services to key populations and are attuned to the country dynamics. In consultation with them we have developed the approach outlined below.

The first and greatest risk is that study participants' identities as persons living with HIV or as members of criminalised or marginalised groups could be shared outside the study. This could lead to stigma, discrimination, loss of employment or housing, social isolation, or risk of violence. A second risk is of retaliation or arrest in countries where key populations are criminalised. A related risk is that participants, including CAT members, might withdraw from the project or even publicly criticise it if they feel that their security is not ensured.

To address these risks, the PI and the Steering Committee are consulting closely with the national organisations and with GNP+ to develop strategies and approaches that mitigate risks. Risk is a standing agenda item for all meetings, to ensure there are routine discussions on these issues. We have planned extensive time in the first phase of the study in establishing routine communications with scheduled meetings and shared updates on our text message groups, as well as building trust and relationships across the consortium through shared activities.

Within the study, participants will never be asked to disclose sensitive information such as HIV status or sexual orientation, and those who volunteer such information during the research project will be reassured that what they say will be anonymized and that data will be stored in a safe and secure manner. Informed consent procedures will be put in place,

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[54] Human Rights Watch (2018), *No choice but to deny who I am: Violence and discrimination against LGBT people in Ghana*. Available from https://www.hrw.org/report/2018/01/08/no-choice-deny-who-i-am/violence-and-discrimination-against-lgbt-p
eople-ghana.

using clear and concise language developed and reviewed by experts in each country to ensure it is consistent with international standards and comprehensible by local community members. The participatory action research approach, which engages participants from the outset included in drafting research protocols, interview guides and research plans, is also a mitigation measure.

All data will be anonymized using codes, and identifiers will be stored separately from field records in a secure and protected place. Specifically, only the socio-demographic data on age, gender, education, employment and town/community of residence of participants will be collected. Information Protective measures will be taken regarding the transfer of data and sharing of data among partners. Participants will be able to withdraw from the project at any time. Given the heightened political sensitivities in Vietnam, all language used to describe the study in Vietnam, including external communications about the study overall, will be developed with advice from the Vietnamese partner organisation.

In an emergency, the Steering Committee and national organisations can draw on extensive contacts with senior officials at UN agencies, UK FCDO, US PEPFAR, and the Global Fund to Fight AIDS, TB and Malaria.

A final possible inconvenience is related to the time required to participate in interviews and FGDs; in particular, for participants who are living with HIV, for participants living in rural areas; for parents of small children; or marginalised groups. All possible efforts will be made to make participation feasible, diverse and inclusive, and to minimise the time commitment required. In addition, minimal benefits will be provided to compensate for participant’s cost of transportation and food and time spent to participate in the research.

8.2 Potential benefits

The findings from this research will be used to improve policies and services, in particular governance of digital health technologies. The findings will be shared with stakeholders, policy makers and service providers in Ghana, Kenya, Vietnam and Colombia to recommend tailored interventions and policy changes to uphold the rights of young adults who use digital technologies.

A subgroup of individual participants who either join the CAT or who participate in training and consultations will benefit from opportunities for learning, leadership and development of skills, knowledge and networks. Our aim is that a broader population will benefit indirectly from generated evidence and improved digital health governance in the four focus countries.

Key informants and focus group participants will not receive incentives, but reimbursement of travel costs and refreshments will be provided, in accordance with the policies already in place at national partner institutions (KELIN, NAP+, VNP+ and Uniandes).

9 Dissemination of results and publication policy

As discussed above, the consortium has developed a shared theory of change, which outlines how our study findings should combine with digital literacy training and youth leadership to contribute to long-term policy impact. STOPAIDS and Privacy International are developing a global policy impact plan in consultation with the full consortium, to be informed by national plans developed by the CATs in each country.

The results of the research will be written up in papers for conferences, and articles for peer-reviewed journals. Additionally, we will develop policy briefs, working papers published on the website of the CIM, and convene webinars with the project partners. The lead author and order of authorship will always be agreed, in accordance with our consortium publications policy, based on substantial contribution to the manuscript, with specific contributions listed in a footnote (or elsewhere in the final article, in accordance with publication policy of the journal).

The choice of journal (or other medium) for publications should be based primarily on the journal's audience, reach, and influence on key stakeholders. Other factors such as speed of publication and chance of acceptance should also be considered. The primary aim of publication should be effective communication and influencing stakeholders as well as academic recognition. Moreover, journal quality (Scimago ranking) and impact factor should also be considered, as well as available resources to pay any publication fees.

Publication in open access journals will be encouraged, dependent on resources. Two routes are available: open access publishing ('gold' open access) or self-archiving where full release can be time limited ('green' open access). A detailed description of the dissemination and publication process has been provided in the publication guideline and authorship policy for the Digital Health and Rights Project.

10 Project management

The Centre for Interdisciplinary Methodologies (CIM) is the coordinating institute. Prof. Sara L.M. Davis will be the Principal Investigator (PI) and coordinator. The PI has led development of the research master protocol and instruments in collaboration with the Research Team and Consortium members as indicated severally in this document. The consortium members (GNP+, KELIN, Restless Development, STOPAIDS, and Universidad de los Andes) have signed a collaboration agreement with University of Warwick which spells out our shared plans and budgets; Privacy International, NAP+ Ghana and VNP+ are sub-granted directly by GNP+.

Professor Catalina Gonzalez Urribe (Universidad de los Andes) will be the national PI in Colombia. Mr. Allan Maleche (KELIN) will be the national PI in Kenya. Ms. Elsie Ayeh (NAP+ Ghana) will be the national PI in Ghana, and Mr. Dong Do Dang (VNP+) will be the national PI in Vietnam. All four of the national Pis previously served in the same role in previous studies conducted by the Digital Health and Rights Project. Ms. Nomtika Mjwana (GNP+) will provide added support and coordination to the national networks in Ghana and Vietnam.

All four national PIs have been fully engaged in the development of the research protocol and research plan and will be fully engaged in development of data collection instruments, including questionnaires and interview guides. They will be responsible for supervising researchers and coordinating communications with the CAT. They are also responsible for seeking local ethical approval in line with local regulations, facilitating contacts with local stakeholders and data collection sites, overseeing data collection (with guidance from the PI and Post-doctoral Research Fellow), contacting the participants, conducting interviews and focus group discussions, coordinating transcription and translation of qualitative data, and collaborating in analysis of data and writing the final reports.

The Consortium has approved a Data Management Policy and Publications Policy to guide our collaboration in research and publications. We have a shared work plan and timeline to coordinate our work, and hold regularly scheduled meetings on a weekly, biweekly or monthly basis to coordinate specific work streams. The full consortium, including CAT members, meets quarterly online to review progress and discuss any shared concerns.

Appendices

Statement for digital ethnography

I (XXX) am joining this [chat group/social media group/listserve/other] on behalf of the Digital Health and Rights Project. The project aims to understand how digital platforms are governed and how this impacts on the experience of young adults.

It is a project led by the Centre for Interdisciplinary Methodologies (CIM) of Warwick, in partnership with [KELIN/NAP+ Ghana/VNP+/Universidad de los Andes/Restless Development] and is funded by Fondation Botnar. As part of the project, we are participating in digital spaces such as this one to understand the broader issues and concerns people have.

I will not directly quote anything said in this [chat group/social media group/listserve/other] and will only use what I learn to identify general issues that the researchers will study in more depth through key informant interviews and focus group discussions.

The moderator[s] of this group have approved my participation, but if you have any questions or concerns, please let me know.

Invitation to Participate in Key Informant Interviews (KIIs)-Young Adults

We (XXX) are inviting you to participate in an Interview as part of the Digital Health and Rights Project. The project aims to promote a just digital future by understanding how young people experience the governance of digital platforms, and how this affects their health. The interview will focus on topics relating to digital literacy and empowerment, digital governance and meaningful participation. We are inviting you because you are a person who may be interested in digital technologies, you live in [COUNTRY], and you are between 18 and 30 years of age.

We expect the research to help in developing policy recommendations. This research is a collaborative and multi-country research project led by the Centre for Interdisciplinary Methodologies, University of Warwick, in partnership with [KELIN/NAP+ Ghana/VNP+ and Universidade de los Andes/Restless Development]. The research is supported by Fondation Botnar.

The interview will take around [45-90] minutes. You are entitled to stop the interview at any time or skip any questions you do not want to answer. In that case we will expunge the interview from our records, nonetheless once the information you provide is analysed, we cannot expunge it as individual information cannot be traced to those who gave them in our research due to the principles of anonymity adopted in this research. All information you provide will be kept confidential and anonymous. The research data may be used for future research by the Digital Health and Rights Project consortium with agreement by the national organization. In addition, three years after the study is concluded, anonymized interview transcripts will be posted in an online repository for up to ten years, to enable other researchers to benefit from the study.

If you agree to participate, please [call/contact XXXXX] and leave your contact details so the research team can reach you.

Please inform other friends who are young people and who use these apps for this research. They can contact the research team [call/contact XXXXX] if they are interested to participate in the research, and we will forward this invitation to them in person or by email.

If you have questions about this study, you may contact the investigator/research team.

[CONTACT DETAILS LOCAL PARTNER]

Invitation to Participate in Key Informant Interviews (KIIs)-Officials

We (XXX) are inviting you to participate in an Interview as an expert on issues that relate to the utility of digital technologies. The Digital Health and Rights Project aims to promote a just digital future by understanding how young people experience the governance of digital platforms, and how this affects their health. The interview will focus on topics relating to digital divides, digital literacy and empowerment, digital governance and meaningful participation. We are inviting you because you are a person who has engaged with issues on policy and governance on digital technologies in the past, and may be interested in digital technologies in the country [COUNTRY] you live or work in.

We expect the research to help in developing policy recommendations. This research is a collaborative and multi-country research project led by the Centre for Interdisciplinary Methodologies, University of Warwick, in partnership with [KELIN/NAP+ Ghana/VNP+ and Universidade de los Andes/Restless Development]. The research is supported by Fondation Botnar.

The interview will take around [45-90] minutes. You are entitled to stop the interview at any time or skip any questions you do not want to answer. In that case we will expunge the interview from our records, nonetheless once the information you provide is analysed, we cannot expunge it as individual information cannot be traced to those who gave them in our research due to the principles of anonymity adopted in this research. All information you provide will be kept confidential and anonymous. The research data may be used for future research by the Digital Health and Rights Project consortium with agreement by the national organization. In addition, three years after the study is concluded, anonymized interview transcripts will be posted in an online repository for up to ten years, to enable other researchers to benefit from the study.

If you agree to participate, please [call/contact XXXXX] and leave your contact details so the research team can reach you.

Please inform other colleagues or experts who may be interested in the issues we will discuss in the interview. They can contact the research team [call/contact XXXXX] if they are interested to participate in the research, and we will forward this invitation to them in person or by email.

If you have questions about this study, you may contact the investigator/research team.

[CONTACT DETAILS LOCAL PARTNER]

Invitation to Participate: Focus Group Discussion (FGD)-Young Adults

We (XXX) are inviting you to participate in a focus group discussion as part of the Digital Health and Rights Project. The project aims to promote a just digital future by understanding how young people experience the governance of digital platforms, and how this affects their health. We are inviting you because you are a person who may be interested in digital technologies, you live in [COUNTRY], and you are between 18 and 30 years of age.

We expect the research to help in developing policy recommendations. This research is a collaborative and multi-country research project led by the Centre for Interdisciplinary Methodologies, University of Warwick, in partnership with [KELIN/NAP+ Ghana/VNP+ and Universidade de los Andes/Restless Development]. The research is supported by Fondation Botnar.

The FGD will take around [60-90] minutes. You are entitled to stop the interview at any time or skip any questions you do not want to answer. However, once your information has been processed and analysed, we cannot expunge it as we cannot trace participants information to them because of the principle of anonymity adopted in this study. All information will be kept confidential and anonymous. You will receive compensation for your transportation and refreshment for your time spent. Please be informed that the research data may be used for future research by the Digital Health and Rights Project consortium with agreement by the national organization. In addition, three years after the study is concluded, anonymized interview transcripts will be posted in an online repository for up to ten years, to enable other researchers to benefit from the study.

If you agree to participate, please [call/contact XXXXX] and leave your contact details so the research team can reach you.

Please inform other friends who are young people and who use these apps of this research. They can contact the research team [call/contact XXXXX] if they are interested to participate in the research, and we will forward this invitation to them in person or by email.

If you have questions about this study, you may contact the investigator/research team.

[CONTACT DETAILS LOCAL PARTNER]

Consent Form for Key Informant Interviews-Young Adults

Title of Project: DIGITAL HEALTH AND RIGHTS: A PARTICIPATORY ACTION RESEARCH PROJECT
IRB Number: [XXX]
Sponsor: Fondation Botnar
Principal Investigator: Sara L.M. Davis, Centre for Interdisciplinary Methodologies, University of Warwick,
sara.davis@warwick.ac.uk
Study Phone Number: phone number

Overview

We are asking you to be part of a research study that explores young adults experiences with digital technologies. A research study is an organized way of collecting information about scientific questions. This form will tell you what you should expect if you agree to be in the study. There are programs in place to make sure that investigators fulfil their obligations listed in this form.

It is your decision whether to join the study. We are doing the research to explore stories and experiences of people in the community who use digital apps for health. If you agree, you will be interviewed only once. You will find more information about what will happen in this study later in this form. The main disadvantages of being in the study is the time you spend in participating in the interviews. You will find more information about potential risks later in this form.

Purpose of the research: The research aims to explore the stories and experiences of young people in their usage of digital technologies. We also wish to learn what impact these technologies have on health and access to health services. We expect the research to provide guidance to UN agencies, aid agencies and health officials about how to protect people's equality, privacy and right to choose.

What Will Happen in This Research Study: The study will be conducted where you live in the town/community of XXX. Before starting the interview, you will be given a copy of this form to read and keep. If you agree, we will decide on a time that works for you to speak with a researcher. You will meet somewhere safe and convenient for you, where you can speak freely and privately without being disturbed or overheard. You will have a conversation with a researcher for 45-90 minutes. The researcher will ask some questions. If there are questions that you are uncomfortable answering, you may refuse to answer. Your participation will be voluntary, and you have the right to leave or end the interview at any time. You can also tell the researcher to delete any part of the interview if you change your mind later. You will not suffer any penalty or lose any benefits to which you are entitled. Your participation is completely up to you. Your decision not to answer any questions or withdraw from the study will not affect your ability to get any health care. However, once the data has been analysed, the information you provide cannot be excluded, given the anonymised ethical principles adopted for this study.

The ways we will protect your privacy and confidentiality are described in a separate section later in this form. We will make an audio recording of the interviews, however if you decide otherwise, we are happy to take notes instead. You will be one of approximately 310 participants who will take part in the study in Ghana, Kenya, Vietnam and Colombia.

Risks: Your participation in this study may involve some possible small risks or inconveniences**.** The first possible risk is that your identity may be disclosed to someone outside of the study. To prevent this from happening, we will not have any of your identifying information in any of the material. We will use unique numbers to identify your information. Your identity will be protected, and only authorized people involved in this research can see the information you have shared in the interview.

A second possible risk of participation is that you may feel inconvenienced because of the time you take to be in the study. We will try our best to keep the study short.

Benefits: You will not have any direct immediate benefits from this study. However, the findings from this research will help in understanding issues and gaps in digital governance, and help us to advise UN agencies, government officials and private companies about how to better include the views of young people in planning and using these apps.

Privacy and confidentiality: We are committed to ensuring that your privacy and confidentiality is always protected. We will not record your name or any information that shows your identity. You will not be signing this form. We will store your information in ways we think are secure. We will store paper files in locked filing cabinets. We will store electronic files in computer systems with password protection and encryption. Your private information will be concealed, and no data will be traced back to you. Only the authorized research team members will have access to the data.

Cost: There are no costs to you for being in this research study.

Payment: Reimbursement of travel expenses will be provided by the organization that engaged you in this study if you incur any because of your participation in this study. There will be no other payment.

Subject's Rights: By consenting to be in this study you do not waive any of your legal rights. Consenting means that you have been given information about this study and that you agree to participate in the study. You will be given a copy of this form to keep. If you do not agree to be in this study or if at any time you withdraw from this study you will not suffer any penalty or lose any benefits to which you are entitled. Your participation is completely up to you. Your decision will not affect your ability to get health care. It will not affect your enrolment in any health plan or benefits you can get.

For more information

If you have any questions, concerns or complaints about this study or your part in it, or require additional information about the research or the [*ORG*], please contact:

National PI	Email / Phone number
National Researcher	Email / Phone number
Organization	ADDRESS /WEBSITE

Consent

By agreeing to be in this research, you are indicating that you have read this form (or it has been read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. If you prefer to provide verbal informed consent, this is witnessed by an individual not connected to the study.

The purpose and nature of the interview have been explained to me.

Please place (✓) to all that apply:

☐ I agree to participate in this study.
☐ I agree to have this interview electronically recorded.
☐ I agree to participate in the study through verbal consent.

ID number of the interviewee: ____

Researcher: ____
Printed name of person conducting consent discussion

I discussed the research and my questions have been answered. I understand what is involved in the study and freely agree to participate.

____ ___________
Signature of interviewee Date

Verbal Consent Witness: ____
Printed name of witness (a person not otherwise associated with the study)

This consent form was read to and apparently understood by the subject in my presence.

____ ___________
Signature of witness Date

Written Consent Form for Key Informant Interviews-Officials

Title of Project: DIGITAL HEALTH AND RIGHTS: A PARTICIPATORY ACTION RESEARCH PROJECT
IRB Number: [XXX]
Sponsor: Fondation Botnar
Principal Investigator: Sara L.M. Davis, Centre for Interdisciplinary Methodologies, University of Warwick,
sara.davis@warwick.ac.uk
Study Phone Number: phone number

Overview

We are asking you to be part of a research study that explores the utility of digital technologies by young adults. This form will tell you what you should expect if you agree to be in the study. There are programs in place to make sure that investigators fulfil their obligations listed in this form.

Purpose of the research: The research aims to explore the stories and experiences of young people in their usage of digital technologies. We also wish to learn what impact these technologies have on health and access to health services. We expect the research to provide guidance to UN agencies, aid agencies and health officials about how to protect people's equality, privacy and right to choose.

What Will Happen in This Research Study: The study will be conducted where you live in the town/community of XXX. Before starting the interview, you will be given a copy of this form to read and keep. If you agree, we will decide on a time that works for you to speak with a researcher. You will meet somewhere safe and convenient for you, where you can speak freely and privately without being disturbed or overheard. You will have a conversation with a researcher for 45-90 minutes. The researcher will ask some questions. If there are questions that you are uncomfortable answering, you may refuse to answer. Your participation will be voluntary, and you have the right to leave or end the interview at any time. You can also tell the researcher to delete any part of the interview if you change your mind later. You will not suffer any penalty or lose any benefits to which you are entitled. Your participation is completely up to you. Your decision not to answer any questions or withdraw from the study will not affect your ability to get any health care. However, once the data has been analysed, the information you provide cannot be excluded, given the anonymised ethical principles adopted for this study.

The ways we will protect your privacy and confidentiality are described in a separate section later in this form. We will make an audio recording of the interviews, however if you decide otherwise, we are happy to take notes instead. You will be one of approximately 310 participants who will take part in the study in Ghana, Kenya, Vietnam and Colombia.

Risks: Your participation in this study may involve some possible small risks or inconveniences**.** The first possible risk is that your identity may be disclosed to someone outside of the study. To prevent this from happening, we will not have any of your identifying information in any of the material. We will use unique numbers to identify your information. Your identity will be protected, and only authorized people involved in this research can see the information you have shared in the interview. Your name and the company or university where you work will not be recorded, and we will record only the title of your occupation.

A second possible risk of participation is that you may feel inconvenienced because of the time you take to be in the study. We will try our best to keep the study short.

Benefits: You will not have any direct immediate benefits from this study. However, the findings from this research will help in understanding issues and gaps in digital governance, and help us to advise UN agencies, government officials and private companies about how to better include the views of young people in planning and using these apps.

Privacy and confidentiality: We are committed to ensuring that your privacy and confidentiality is always protected. We will not record your name or any information that shows your identity. You will not be signing this form. We will store your information in ways we think are secure. We will store paper files in locked filing cabinets. We will store electronic files in computer systems with password protection and encryption. Your private information will be concealed, and no data will be traced back to you. Only the authorized research team members will have access to the data.

Cost: There are no costs to you for being in this research study.

Payment: Reimbursement of travel expenses will be provided by the organization that engaged you in this study if you incur any because of this research. There will be no other payment.

Subject's Rights: By consenting to be in this study you do not waive any of your legal rights. Consenting means that you have read the information about this study and that you agree to participate in the study. You will be given a copy of this form to keep. If you do not agree to be in this study or if at any time you withdraw from this study you can freely walk away. Your participation is completely up to you.

For more information

If you have any questions, concerns or complaints about this study or your part in it, or require additional information about the research or the [*ORG*], please contact:

National PI	Email / Phone number
National Researcher	Email / Phone number
Organization	ADDRESS /WEBSITE

Consent

By agreeing to be in this research, you are indicating that you have read this form, and that your questions about the study have been answered to your satisfaction by the researchers, and that you voluntarily agree to participate in this research study.

I understand the purpose and nature of the interview.

Please place (✓) to all that apply:

☐ I agree to participate in this study.
☐ I agree to have this interview electronically recorded.

ID number of the interviewee: ____

Researcher: ____
Printed name of person conducting consent discussion

I discussed the research and my questions have been answered. I understand what is involved in the study and freely agree to participate.

____ ____________
Signature of interviewee Date

Consent Form for Focus Group Discussions (FGDs)-Young Adults

Title of Project: DIGITAL HEALTH AND RIGHTS: A PARTICIPATORY ACTION RESEARCH PROJECT
IRB Number: [XXX]
Sponsor: Fondation Botnar
Principal Investigator: Sara L.M. Davis, Centre for Interdisciplinary Methodologies, University of Warwick,
sara.davis@warwick.ac.uk
Study Phone Number: phone number

Overview

We are asking you to be part of a research that explores young adults' opinion on digital technologies. A research study is an organized way of collecting information about scientific questions. This form will tell you what you should expect if you agree to be in the study. There are steps in place to make sure that investigators fulfil their obligations listed in this form.

It is your decision whether to join the study. We are doing the research to explore stories and experiences of people in the community who use digital apps for health. You will find more information about what will happen in this study later in this form. The main disadvantages of being in the study is the time you spend in participating in the FGD. You will find more information about potential risks later in this form.

Purpose of the research: The research aims to explore the stories and experiences of young people in their usage of digital technologies. We also wish to learn what impact these technologies have on health and access to health services. We expect the research to provide guidance to UN agencies, aid agencies and health officials about how to protect people's equality, privacy and right to choose.

What Will Happen in This Research Study: The study will be conducted where you live in your city of XXX. Before starting the FGD, you will be given a copy of this form to read and keep. If you agree, we will decide on a time that works for you to speak with a researcher. You will meet somewhere safe and convenient for you, where you can speak freely and privately without being disturbed or overheard. You will have a conversation with a researcher for 60-90 minutes to tell your story. The researcher will ask some questions. If there are questions that you are uncomfortable answering, you may refuse to answer. Your participation will be voluntary, and you have the right to leave or end the FGD at any time however the FGD will not stop after you have left. You can also tell the researcher to delete any part of the contributions you make if you change your mind later. You will not suffer any penalty or lose any benefits to which you are entitled. Your participation is completely up to you. Your decision not to answer any questions or withdraw from the study will not affect your ability to get any health care. However, once the recording is completed, your answers cannot be excluded, because we will anonymise all data, and your answers cannot be traced to an individual.

The ways we will protect your privacy and confidentiality are described in a separate section later in this form. We will make an audio recording of the group discussions. You will be one of approximately 310 participants who will take part in the study in Ghana, Kenya, Vietnam and Colombia.

Risks: Your participation in this study may involve some possible risks or inconveniences**.** The first possible risk is that your identity may be disclosed to someone outside of the study. To prevent this from happening, we will not have any of your identifying information in any of the material. We will invite you to choose a made-up name for the focus group discussion, and we will use unique numbers to identify your information in our notes. Your identity will be protected, and only authorized people involved in this research can see the information you have shared in the group discussions.

A second possible risk of participation is that you may feel inconvenienced because of the time you take to be in the study. We will try our best to keep the study short. You will also receive a symbolic payment to cover your transportation costs, and some light refreshments.

Benefits: You will not have any direct immediate benefits from this study. However, the findings from this research will help in understanding the challenges young people face and help us to advise UN agencies, government officials and private companies about how to better include the views of young people in planning and using these apps. If you are interested to participate in future free of charge trainings on digital literacy and empowerment, an opportunity to sign up for more information will be provided at the end of the focus group discussion; however, this is purely voluntary, and your name will not be linked to the focus group discussion in any way.

Privacy and confidentiality: We are committed to ensuring that your privacy and confidentiality is always protected. We will not record your name or any information that shows your identity. You will not be signing this form. We will store your information in ways we think are secure. We will store paper files in locked filing cabinets. We will store electronic files in computer systems with password protection and encryption. Your private information will be concealed, and no data will be traced back to you. Only the authorized research team members will have access to the data. [*For FGD: We will ask everyone in the focus group not to talk about the discussions outside the group. However, we can't promise that everyone will keep what you say confidential.]* We will share research findings where we have removed anything that indicate your identity. Such sharing includes publishing results in a scientific book or journal and using research data in future studies, done by us or by other scientists.

Cost: There are no costs to you for being in this research study.

Payment: In addition to reimbursement of travel expenses, you will receive some light refreshments as a sign of appreciation for the time you have taken. This will be provided by the organization that engaged you in this study.

Subject's Rights: By consenting to be in this study you do not waive any of your legal rights. Consenting means that you have been given information about this study and that you agree to participate in the study. You will be given a copy of this form to keep. If you do not agree to be in this study or if at any time you withdraw from this study, you will not suffer any penalty or lose any benefits to which you are entitled. Your participation is completely up to you. Your decision will not affect your ability to get health care. It will not affect your enrolment in any health plan or benefits you can get.

If you prefer not to sign your name, we can provide the option of verbal informed consent with a witness.

For more information

If you have any questions, concerns or complaints about this study or your part in it, or require additional information about the research or the [*ORG*], please contact:

National PI	Email / Phone number
National Researcher	Email / Phone number
Organization	ADDRESS /WEBSITE

Consent

By agreeing to be in this research, you are indicating that you have read this form (or it has been read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study.

The purpose and nature of the FGD have been explained to me.

Please place (✓) to all that apply:

☐ I agree to participate in this study.
☐ I agree to have this interview electronically recorded.
☐ I agree to participate in this study through verbal consent.

ID number of the FGD: ____

Researcher: ____
Printed name of person conducting consent discussion

I have personally explained the research to the above-named subject and answered all questions. I believe that the participant understands what is involved in the study and freely agrees to participate.

____ ____________
Signature of person providing consent Date

Verbal consent witness: ____
Printed name of witness of verbal informed consent (a person not otherwise associated with the study)

This consent form was read to and apparently understood by the subject in my presence.

____ ____________
Signature of witness Date

Case sheet

CONFIDENTIAL INFORMATION! Keep in a secure place and do not share with others.

Identifier code	Interview date	Self-reported Gender	Age – between 18-30	Employment	Education (primary, secondary, post-secondary)	Town/ community of residence	Informed consent?

Key informant interview debrief sheet

Please complete immediately after the interview, with any member of the team who participated (e.g. note taker).

Interviewer (your name)	
Identifier code	
Gender	
Age	
Employment	
Country	
Name of the locality where the interview took place	
Interview date	
Interview time of day	
Interview recorded	**yes [INTERVIEW RECORDING ID]** **yes [INTERVIEW RECORDING ID], but only partially, [*explain why*]** **no**
Other persons present during the interview, including interpreters	**Yes (who)** **No**
Language of the interview	
Any notes on sound quality [background noise, interruptions]	
Description of setting [In office, at home, etc]	
How would you describe the overall atmosphere of the interview?	
Were there any problems or concerns with the topic list?	
Did you discuss any topics that were not on the list? If so, what were they?	
Is there anything you need to follow up on with the interviewee – referrals, information, additional questions?	

Notes (*Write here any notes you took during the interview*)

Focus Group Discussion (FGD) Debrief sheet

Immediately after the focus group please do the following:

- Listen to recording (spot check throughout) to ensure it worked
- Debrief for moderator, notetaker, or anyone who supported the FGD and use this form to guide the discussion.
- Label and send recording and transcription to secure location.

FGD number	
Focus Group Facilitator	
Focus Group assistant	
Pseudonyms used, if any	
Country, City or Town	
Location of FGD (e.g. hotel meeting room, etc.)	
Date of FGD	
Time of FGD	
FGD recorded	**yes [FGD RECORDING ID]** **yes [FGD RECORDING ID], but only partially, [*explain why*]** **no**
Other persons present during the FGD, including interpreters	**Yes (who)** **No**
Language of the FGD	
Any notes on sound quality [background noise, interruptions]	
Did the location affect the discussion in any way? If so, explain	
How were participants recruited for this FGD? (eg mobilized by a specific NGO)	
What themes or topics came up in the FGD?	
Were there any surprises? Did you need to make any changes to your plans to accommodate requests or needs of participants?	

Did you discuss any topics that were not on the interview guide? If so, what were they?	
Is there anything you need to follow up on with the participants – referrals, information?	
Any lessons learned for next time?	