



UNIVERSITY
OF WARWICK

DHRP
Digital Health & Rights Project

**RESTLESS
DEVELOPMENT**

Meaningful Participation of Young Adults and Civil Society in Digital Governance Consultations

Research Brief



Executive Summary

As the digital transformation continues to grow, international organisations increasingly recognise the need to consult with young adults and civil society as strategic stakeholders who should have a voice in shaping policy. The resulting growth in youth consultations, councils and convening on digital governance and health is promising, but run the risk of being 'tokenistic', with superficial inclusion that fails to influence policy or structural change. This brief by the Digital Health and Rights Project shares findings from qualitative research with 46 young adults and 4 civil society leaders from Colombia, Ghana, Kenya and Vietnam who participated in global, regional, national and local consultations on digital health, rights and governance between May 2024 and September 2025. It finds that meaningful participation in digital governance demands intentional design, including diverse representation; opportunities for co-creation; iterative cycles of feedback and input; and resources for travel, translation, briefing and debriefing.

Study Highlights

- Community Advisory Team (CAT) members appreciated opportunities to represent their diverse communities, learn, and build networks
- A growing number of digital governance convenings—but unequal access and participation among countries
- Some CAT members felt dismissed or ignored, or struggled to participate
- While many participants had positive experiences, there were few concrete policy outcomes during the study period



What is at Stake?

The world is home to the largest generation of youth in human history. While the United Nations predicted a 7 per cent increase in youth population to nearly 1.3 billion by 2030, in fact, the number of 15- to 29-year-olds had already reached an estimated 1.8 billion in 2022.^{1, 2} The role of civil society organisations (CSOs) in global health governance and implementation has also risen since the 1990s.³

Young people and CSOs can be a positive force for accelerating progress towards the 2030 Agenda for Sustainable Development.⁴ Indeed, as the largest and most digitised youth generation to date, youth voice in digital governance is critical. The right to participation in decision-making is grounded in international human rights to information, freedom of expression, peaceful assembly and association, and freedom of political and other opinion, and is widely accepted in development cooperation.⁵ The 2024 Pact for the Future established principles for meaningful youth participation in UN governance processes.⁶ STOPAIDS has also developed [Principles for the Meaningful Involvement of Communities and Civil Society in Global Health Governance](#), setting out principles for both global health institutions and for civil society to guide participation in global governance boards.

In practice, however, young peoples' human rights are often at risk, and they are frequently locked out of decision-making that affects their lives. The 2021 Lancet and Financial Times Commission review of digital health governance found that youth are most affected by the digital transformation of health, but frequently omitted from policy discussions.⁷ When consultations are poorly defined, resourced and executed, the resulting engagement only reinforces existing inequalities; Wong and colleagues argue that youth may be "museumised" in digital health consultations: "put on display, claimed to be represented by those in power, and yet kept unheard behind a glass wall."⁸

To promote greater accountability for meaningful participation, and understand some of the factors shaping meaningful vs. "museumised" participation in digital governance convenings and consultations, the Digital Health and Rights Project consortium studied how young adults and civil society in our consortium experienced their roles in digital governance convenings and consultations, such as those held at the Internet Governance Forum, at the World Health Organization, and in national and regional consultations in Africa, Asia and Latin America, during the first eighteen months of our 2023-26 project, The Future of Human Rights in the Digital Age.





Digital Health and Rights Project (DHRP) and Community Advisory Teams (CATs)

The Digital Health and Rights Project (DHRP) was established in 2019 as a consortium of a social scientists, human rights lawyers, health advocates, rights advocates, and global and national networks of people living with HIV: a total of 10 organisations across four continents (Africa, Europe, Latin America and South-East Asia). DHRP's transnational participatory action research approach to research, advocacy and governance is grounded in Community Advisory Teams (CATs) established in Colombia, Ghana, Kenya and Vietnam.

The CATs, made up of 10 to 14 young adults and civil society leaders, are hosted by national institutions (KELIN [Kenya], Universidad de los Andes [Colombia], and VNP+ [Vietnam]). Restless Development coached CAT members with training in human rights and youth leadership. The CATs co-led every aspect of the four-country study that produced [Paying the Costs of Connection: Human rights of young adults in the digital age in Colombia, Ghana, Kenya and Vietnam.](#)⁹ Working with the national institutions above and with STOPAIDS and Privacy International, who led a global Advocacy Working Group, CAT members developed national advocacy plans to drive change through consultations, blogs, letter-writing, and direct conversations with officials. Their plans aimed to ensure the study findings and recommendations reached those who could make a difference. CAT members also spoke in regional and global meetings, including Internet Governance Forum, World Health Organization workshops, UN human rights consultations, and more. This brief is based on their reflections on advocacy during the first half of the three-year project.

About this study

Early career researchers at the Centre for Interdisciplinary Methodologies (CIM), University of Warwick, which hosted DHRP during 2023-26, collaborated with a Research Manager and Head of Programmes at Restless Development, an international CSO, to organise periodic reflections with young adults ages 18-30 and civil society leaders on the CATs. The semi-structured reflections explored experiences at national, regional and global consultations and convening, including community-led workshops in Vietnam; regional African meetings on digital health in Africa; side events at the World Health Assembly in Geneva; the LAC-IGF; and meetings on the sidelines of the UN General Assembly during approval of Pact for the Future: a total of two local events, twelve national events, ten multi-country/regional events, and twelve global digital governance convening. Throughout, Restless Development convened leadership trainings and invited young adults in the CATs to keep diaries and notes of their experiences and observations.

Researchers held 11 reflective discussions with 46 CAT members and 4 CSO leaders between May 2024 to September 2025, including 11 from Colombia, 12 from Ghana, 12 from Kenya, and 11 from Vietnam. They represented diverse sexual orientations and gender identities (including men, women, trans*, bisexual, queer, non-binary). Simultaneous interpreters assisted in Vietnamese and Spanish. Ethical approval was obtained from University of Warwick and in each country, and anonymity was safeguarded in transcripts. Recordings were transcribed and translated into English. The research team employed a collaborative analytical approach with thematic coding on Dedoose. Given the limited sample size and the number of events under consideration, our results may not be generalisable. Nonetheless, our choice of qualitative methods offers insights into young adult and civil society participation in digital governance convening.

Key Findings

Unequal access to consultations and events

Young adults described differing levels and forms of access among Colombia, Ghana, Kenya and Vietnam, though travel and participation costs were largely funded and facilitated by DHRP. Access was mediated by a variety of factors, including personal connections of the host institutions, and language and visa barriers. In Kenya, CAT members had opportunities to share recommendations in national policy consultations, brokered by the host institution (KELIN) which holds a prominent role in digital health governance. Colombian, Kenyan and Ghanaian CAT representatives all participated in UN and International Organisation-led convenings, as well as some regional convening in Africa and Latin America such as the Africa Internet Governance Forum and the Internet Governance Forum for American Countries (LAC-IGF). During the study period, Vietnamese participation was limited to active participation in local events, which they organised themselves given the country's constraints on civic space: or to passive participation in official national dissemination events (after the study period, some participated in regional South-East Asian events).

“Members of our community have very few opportunities to participate. As people living with HIV, or key populations like sex workers, we haven’t had any chances to participate in digital health events.”

Vietnam Community Advisory Team member



Paradox of participation: Representation, yet feeling dismissed

Those who did participate had predominantly positive experiences, but mixed concerns. Many CAT members described pride in representing their communities (including people living with HIV, and key populations, including sex workers, trans* and non-binary people, and gay men and other men who have sex with men). Many also said they enjoyed networking and movement-building.

However, some felt dismissed by officials and older people, and noted elitism and lack of diversity; given that many youth leaders supported to participate in digital governance convenings are medical students or computer scientists. Global convening on health and digital governance were seen by some as dominated by the Global North.

Some CAT members encountered language barriers, or challenges with intervening given technical content and complex governance processes. Many reported that consultation organisers failed to provide feedback after the event on whether the input shared had led to policy outcomes.

“There were men, gays, trans people, gender-fluid people. It was not only diverse in gender identities but also in different subjects, and they were in different professional groups.”

Colombia Community Advisory Team member



“I agree that feedback is always a challenge. Barely do they ever give us feedback. They will just send in a thank you email for attending, “We shall be giving you feedback on follow-ups, on the discussions that were had.” But just as I mentioned, for the government strategy meeting, no feedback!”

Kenya Community Advisory Team member

Meaningful Participation: Perspectives

When asked to define what meaningful participation meant to them, CAT member reflections pivoted around three major themes: co-design, leadership, and active involvement. Some argued that for their participation to be meaningful within digital health governance, they should be involved in co-design of policy processes from inception. When young people are not engaged from the outset, they noted, this limits opportunities for leadership roles; visible leadership in decision-making was cited as a significant marker of meaningful participation. Other CAT members described meaningful participation meant that they were actively involved in all stages, from co-design to leadership roles, to consistent input until the end of an initiative, policy process or intervention.

“Meaningful youth participation is [being] actively involved in decision-making, actions and programs that affect our lives.”

Ghana Community Advisory Team member

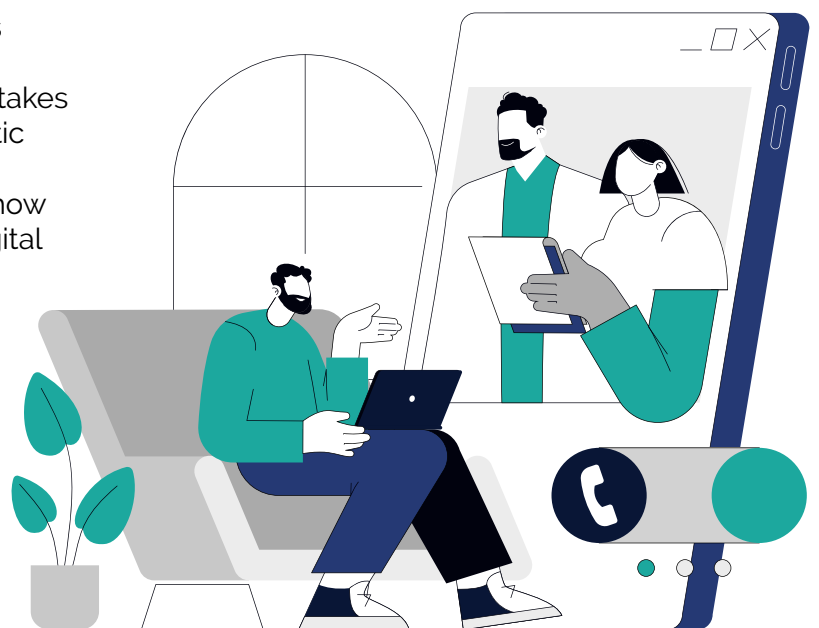


Power, participation and policy outcome

While attendance at national, regional, and international consultations offered speaking and networking roles for CAT members, opportunities for co-creation and leadership appear to have been minimal (apart from within some of the events organised within the DHRP consortium). Most events that CAT members participated in during this period were public conferences and/or dissemination events. Few involved decision-making or governance of digital health technologies or policies. Some CAT members did attend national digital health policy consultations in Kenya, but their views of their actual impact on resulting policy decisions were varied. Overall, the CAT reflection discussions only identified four instances in which there were clear policy outcomes linked to CAT member participation.

The findings from this study open new questions about the role of digital governance events to impact policy outcomes for youth and civil society who participate as speakers, panelists and participants. Digital health governance is diffuse, and much decision-making currently takes place behind closed doors, without democratic oversight. While the study answered some questions, other questions about power and how it is wielded, transacted and utilised in the digital age have yet to be fully answered.

Do digital health convening and conferences influence policy agendas and governance decisions, and if so, how? To what degree are all participants in such conferences (of any age) shaping an agenda on the one hand, or “museumised” on the other? Where are digital health governance decisions made, and who is at the table?



Policy Recommendations

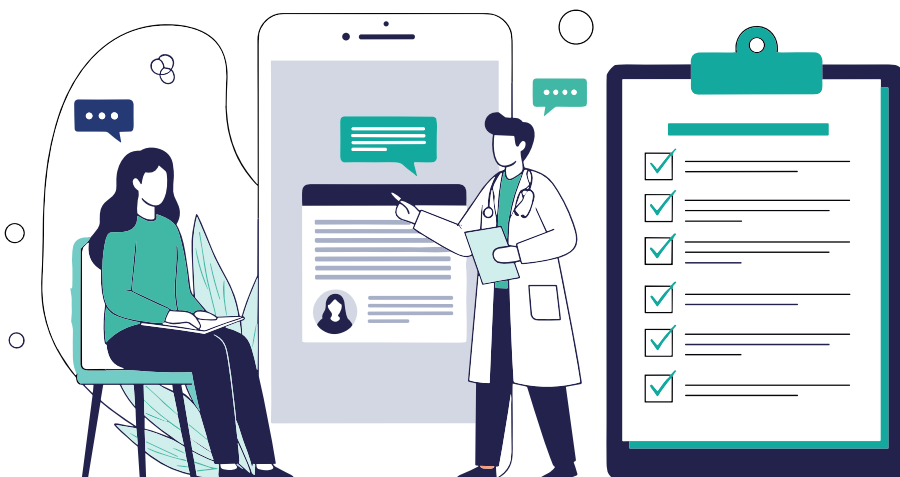
Based on the study findings above, we offer five recommendations to strengthen meaningful participation of young adults and civil society in digital health governance at national, regional and global levels. These are also informed by the STOPAIDS principles, noted above, and the Global Network of Young People Living with HIV (Y+ Global) We Matter, Value Us guideline on ethical engagement of young people living with HIV.

- 1. Co-creation, leadership, and iterative participation** - Digital policy and governance convening or events should promote inclusive design, and diversity of representation, moving beyond elites with medical and technical expertise to include diverse communities whose rights must be upheld in digital governance. Consultations should embody an iterative cycle of co-planning, co-creation, implementation, evaluation and accountability, with clear leadership roles for young adults and civil society who represent those communities.
- 2. Resourcing and capacity building** - Youth representatives should be supported to participate in digital policy and governance consultations with funding to facilitate travel, translation and interpretation support, and time remuneration. This should include investment in digital literacy, digital citizenship and digital rights (or as DHRP refers to this, digital empowerment). CAT members also urged support, as provided by DHRP partner Restless Development, for advance training to give them the knowledge, tools, and advocacy skills (e.g. how to intervene, understand policy processes, and long-term impact) to enable their meaningful participation, consistent with recommendations from STOPAIDS and Y+ Global.
- 3. Transparency, accountability and feedback** - Consultation organisers should provide feedback to youth participants within a reasonable period after the event. Since meaningful participation for young adults and civil society represents a progressive engagement with policies that affect their daily lives, it is imperative they know the outcomes of their participation to maintain respect and trust. Giving feedback also helps to build capacity to ensure future inputs are relevant, and to identify appropriate spaces for channelling limited resources.

4. Decision making - Organisers should intentionally include young adults in decision-making structures with leadership roles, a finding also consistent with STOPAIDS principles.¹⁰ In DHRP this has been institutionalised at each level of decision-making for our £5 million project: each CAT is represented on our transnational project steering committee with elected representatives who exercise equal voting rights with the project principal investigator and senior executives. Far from disrupting governance, these roles have shaped project implementation, grounded governance decisions in community-level realities, improved transparency and information flows, sped removal of bottlenecks in the project, and provided a consistent source of inspiration. We further recommend future research into digital rights and digital health governance, to understand how decision-making is structured, who is at the table, and where there are (or should be) clear opportunities for youth and civil society participation.

5. Youth-centredness - Digital health policy and governance convening on issues concerning young people should be curated by, co-led with, and made accountable to them. Often, officials and experts assume that they know better than young people and community members on issues that affect their daily lives. A paternalistic (instead of a collaborative) logic risks infecting digital health policy and governance systems. This kills initiatives and veils innovative ideas from young minds that have the potential to shape successful implementation of digital technologies. We concur with the Lancet and FT Commission in affirming that the future of health governance needs youth voices at the forefront.¹¹

Our Advocacy Toolbox is designed to strengthen meaningful youth participation in decision-making spaces. It provides templates and tools to help young advocates turn participation into impact by preparing messages before events, engaging strategically during them, and sustaining outcomes afterwards. It is available for free in English, Spanish, and Vietnamese at <https://cods.uniandes.edu.co/advocacy-kit/>.



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