DIGITAL HEALTH AND RIGHTS:

Reflections for Action

Workshop report

19-20 January 2023

GENEVA GRADUATE INSTITUTE | GLOBAL HEALTH CENTRE

FONDATION BROCHER

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FOREWORD

Sara (Meg) Davis, Ph.D.

Principal Investigator, Digital Health and Rights Project

The Digital Health and Rights Project began in 2018, when the Global Fund to Fight AIDS, TB and Malaria announced new partnerships with Mastercard and Google. Talking to civil society leaders on the Board of the Fund, it became clear that digitization and related private sector partnerships raised many questions we could not yet answer. While we were genuinely excited about the promise of tech, we also wondered about the complex risks digitization might bring to women and to communities living with and affected by TB and HIV, who already face so many forms of inequality, discrimination and violence. As the HIV sector has a long history of struggling to produce accurate data for decision-making, how might tools and algorithms grounded in uneven datasets amplify inequalities?

The Digital Health and Rights Project grew from those discussions, and our consortium grew to include social scientists, civil society activists, and leaders of networks representing youth and communities living with HIV. Our monthly video calls probed questions about human rights, decoloniality, feminism, and diverse forms of inclusion and exclusion. We thought about how we might create new knowledge and new forms of solidarity by drawing on our diverse forms of experience and expertise.

Working together in Bangladesh, Colombia, Ghana, Kenya and Vietnam, we developed new empirical evidence using a transnational Participatory Action Research (PAR) approach. We contributed to a forthcoming report to the UN Human Rights Council by the UN Special Rapporteur on the Right to Health, Dr. Tlaleng Mofokeng, on digital innovation, technologies, and the right to health. Civil society in our consortium held consultations to write submissions for her report. We shared our findings and recommendations with UN agencies, the Global Fund, health officials, and health donor agencies.

In January 2023, we all took a step back from this intense work to meet for two days at the beautiful Fondation Brocher in Hermance, Switzerland to delve into these questions:

➜ **What are human rights in the context of digitization of health, and what are the roles of diverse duty-bearers to respect, protect, promote and fulfil these rights?**

➜ **What can we learn from ongoing efforts to ensure equitable access to medicines and health technologies, address human rights concerns about health data gathering (such as molecular HIV surveillance), engage young people living with and affected by HIV, and ensure meaningful participation in global health governance by affected communities?**

➜ **Given critiques of human rights from some decolonial and other advocates, what kind of human rights do we need in the digital future?**

We are grateful to the Fondation Brocher and the Open Society University Network for making the workshop possible, and to Fondation Botnar for continuing support. A huge thank you to Alice Baroni, Agathe Nguyen-Huynh and Moe Shiojiri as well. Our report shares highlights from an inspiring two days in the hope it can spark broader reflections - and action - to promote human rights in the digital age.

Thursday, 19 January, 2023

OPENING PROVOCATION:

REFRESHING HUMAN RIGHTS

Prof. Paul Hunt (New Zealand Chief Human Rights Commissioner)

Prof. Hunt shared some thoughts on human rights, and in particular the need to address inequalities, engage more diverse and broader publics, and dismantle the legacy of colonialism. He presented features of what might form part of a postcolonial human and indigenous rights. These included a set of values (care, trust, community, kinship, stewardship of the environment, respect, dignity, decency, fairness, belonging, responsibility, partnership, participation); and a wide spectrum of human rights, including civil and political rights, workers' rights, social and cultural rights, indigenous peoples' rights, the right to a healthy environment, and the rights to non-discrimination, equality and equity.

Furthermore, he called for post-colonial human and indigenous rights to be grounded in epistemologies that encompass indigenous knowledge. Rights should be grounded in relational responsibilities that individuals have to each other, including the responsibility to build harmonious relationships with communities and with the earth and sky. Powerful companies should also be recognized as having human rights responsibilities. Prof. Hunt argued that this approach to human rights must strike fair and reasonable balances among human rights, and develop new, non-judicial forms of accountability. Human rights should also be grounded in

intergenerationality. Lastly, he called for accountability through processes of truth-telling and peaceful reconciliation.

Prof. Hunt's opening comments were welcomed by the group, and followed by a discussion around the challenges of reimagining different forms of collective partnerships, the challenge of conceptualising duty bearers in the context of interconnected digital networks of people, and the importance of embracing a systems-view of life as we re-think human rights.

PANEL:
HUMAN RIGHTS IN THE DIGITAL AGE

SPEAKERS: *Scott Campbell (OHCHR), Alexandrine Pirlot de Corbion (Privacy International)*
DISCUSSANT: *Stefan Germann (Fondation Botnar)*

The speakers discussed the importance, the meaning and the different ways of putting human rights at the heart of tech governance. Digital technologies were described as both enablers to realise human rights and as potential threats to their promotion and protection with important risks in terms of privacy, exclusion, discrimination, violence, mis- and disinformation, economic exploitation, and surveillance.

The speakers addressed the roles and responsibilities of states in terms of legislation and regulation of the private sector; of private companies in ensuring they align to human rights principles as articulated in the UN Guiding Principles on Business and Human Rights; and of the UN both in promoting the centrality of human rights in governance of tech, and also as a model in its own use of technology.

This was followed by a conversation on the real-world implications of putting the right to privacy at the centre of tech governance – or failing to do so. Speakers critiqued the unequal power dynamics in policy-making regarding digital health, with human rights defenders and affected communities still needing to make the case for a seat at the table. They also raised concerns about the lack of evidence and evaluations of some digital tools used in health, and the lack of normative guidance to ensure digital health meets quality standards. Speakers also discussed a conceptual shift from 'digital health' to 'human rights in a digital age'. They discussed the need for new future visions and greater anticipatory thinking by the human rights community, given the rapid speed of technological development.

The discussion then opened to the broader workshop. It focused on the role of communities and civil society and the urgent need to build capacity to enable them to meaningfully engage in decision-making. Participants also discussed the issue of cross-border data flows, and the type of evidence and advocacy needed to push the discussion on human rights in digital governance.

PANEL: DIGITAL HEALTH AND RIGHTS:

PARTICIPATORY ACTION RESEARCH (PAR) IN BANGLADESH, COLOMBIA, GHANA, KENYA AND VIETNAM

SPEAKERS: Nomtika Mjwana (GNP+), Farzana Misha (BRAC), Javier Guerrero Castro (UniAndes), Sara (Meg) Davis (Graduate Institute)

DISCUSSANT: Tigest Tamrat (WHO)

The speakers presented the Digital Health and Rights Project (DHRP) consortium, a unique collaboration for research, education and policy action, and its multi-country qualitative study. The study aims to understand how young people in low- and middle-income countries (LMICs) experience the impact of digitization on their human rights, including their right to health.

The first phase of the study took place in Ghana, Kenya, and Vietnam, and used a Participatory Action Research (PAR) approach in which members of the community under study participated in design, data-gathering, data analysis and writing. The study utilised mixed methods (desk review, digital ethnography, focus group discussions, key informant interviews). The research team, which included members of the community under study, found that young people felt empowered through accessing health information online and could create 'safe spaces' there. However, they found that this empowerment was not available to all: gender and multiple other digital divides create barriers to access and empowerment online. Young people in Ghana, Kenya and Vietnam disclosed numerous harms linked to their use of mobile phones to access health information/services, including cyberbullying, stalking, harassment, and more. They shared concerns regarding health misinformation, and about state and corporate surveillance given criminalization and related taboos. The study calls for digital literacy and empowerment, meaningful engagement of young people, regulation and human-centred design in digital health.

Phase two of the study, in Bangladesh and Colombia, used a community-engaged approach, in which community-led organisations were less engaged in the research and more in the dissemination phase. The study was still ongoing at the time of the workshop. The emerging findings indicated that strong divides persist according to one's place of residence (rural/urban) and gender identity.

The speakers reflected on the benefits and challenges of participatory action research. They highlighted that it required greater effort than traditional research, but that community involvement led to access to spaces and disclosures they would not have accessed otherwise. Moreover, they highlighted the crucial role of civil society groups as thought partners.

The floor was then opened to all workshop participants, who discussed the importance of access to technology and digital literacy for all. Participants also raised the tensions between bridging the digital divide and protecting privacy from digital services, and the fact that some people may simply wish to opt out of digital technology in order to avoid surveillance. They debated the different meanings and values of privacy for different people, and the role of the WHO, other UN agencies, and funders in promoting a human rights approach in digital health. Lastly, participants discussed the importance of using decolonization/feminist frameworks and human/systems-centred approaches, of bringing more people to the table and ensuring their voices are equal, and of building on collective knowledge to think about the future.

PANEL: DATA AND DISPLACEMENT

SPEAKERS: *Briony Jones (University of Warwick), Patrick Eba and colleague (UNHCR)*
DISCUSSANT: *Monique Beerli (Graduate Institute)*

The panel presented the results and recommendations from the Data and Displacement Project, a qualitative study involving internally displaced persons (IDPs) in Nigeria and South Sudan. Some operational and ethical challenges were outlined in regards to data collection in those settings, such as fragmentary data gathering by humanitarian organisations, data fatigue due to repeated collection, lack of capacity for data collection, lack of training of teams, lack of follow-up and lack of informed consent. Recommendations included the need for data minimisation, and for clearer guidelines to determine when data should or should not be gathered, better sharing of data with IDPs themselves, promoting empowerment and agency of IDPs in data gathering, and training of humanitarian professionals in data ethics.

At the same time, it was noted that international organisations need data to ensure that the estimated 100 million forcibly displaced persons globally receive protection and solutions, a priority for the UN High Commissioner for Refugees (UNHCR). UN agencies such as UNHCR are guided by a set of policies and principles underpinning data collection in humanitarian settings, and the existing policies and guidance used by UNHCR; this includes the principle of retention limitation (i.e. not retaining people's data longer than necessary).

The discussion highlighted the relationship between data and purpose. Speakers noted that humanitarian data might serve other purposes than offering support to forcibly displaced persons, such as competition between humanitarian organisations. They explored power dynamics between diverse actors in humanitarian action, the limits of self-regulation, and the need for accountability mechanisms.

The floor was then opened for a conversation with all participants, who highlighted the importance of community involvement in data collection, including in the design of data categories. However, it was also raised that community-led data has its limitations and that security risks are acute. Speakers called on donor agencies to not only demand reporting on data and indicators, but also allocate resources to data collection and require staff training and clear informed-consent processes. On the latter, a conversation was engaged on the ethical challenges of obtaining informed consent from persons coming from violence, fear and in a position of vulnerability. Lastly, participants raised the need for humanitarian data interoperability.

ROUNDTABLE DISCUSSION: WHAT KIND OF DIGITAL EMPOWERMENT DO YOUNG PEOPLE WANT?

SPEAKERS: *Tinashe Rufurwadzo (Y+ Global), Priscilla Addo (YHAG)*

CHAIR: *Rosanne Palmer-White (Restless Development)*

The speakers discussed what 'digital empowerment' means to young people: maximising the potential of young people to make use of digital technologies by ensuring equal access, and by ensuring young people know their digital rights, how to manage their data, how to protect themselves from threats online, and how to differentiate trusted sources from misinformation.

They discussed the benefits of the digital transformation for young people, which include the availability of centralised databases; eliminating the need to travel to healthcare facilities, saving time and transport costs; and that digital technologies can help young people better monitor their own health while connecting them to peer communities. Digital tools can rapidly give young people resources in emergencies, e.g. gender-based violence.

The panellists also highlighted challenges for young people in the digital age. These include digital divides, misinformation on social media, lack of guidance and support in navigating digital health services, security and privacy issues (e.g. risk of disclosure of HIV status or sexual and gender identity), and the lack of capacity-building resources. The speakers shared concrete advice to meaningfully engage young people, highlighting the "nothing for us, without us" principle. They shared new guidelines by Y+ Global on the meaningful and ethical engagement of young people with a set of core principles derived from their experience and consultation.

The speakers advised organisations to be transparent about funding and limitations, to ensure that the team working with young people are non-judgemental, avoid technical jargon and promote continuous mentoring of young leaders. These recommendations and the practical guidance were warmly appreciated by the full workshop.

PANEL: DIGITAL HEALTH, DIGITAL IDENTITY AND DATA RIGHTS IN EAST AFRICA

SPEAKERS: *Sharifah Sekalala (University of Warwick), Brian Kiira (ISER)*

DISCUSSANT: *Julie Billaud (Graduate Institute)*

The speakers presented a study analysing how health apps are operating in practice and existing regulatory frameworks in Uganda, Kenya and South Africa. Based on interviews, preliminary results reveal numerous concerns around (1) the pressure to collect data to innovate versus the principle of data minimisation, and (2) the challenge of regulation versus the fast pace of digital innovations. Due to a lack of data storage capacity in Sub-Saharan Africa, data is often stored away from the continent. Mobile apps for health create new challenges given their often short temporal lives, and the related commodification and marketisation of health.

A second study of Uganda's National Digital ID system finds it has led to the exclusion of the poorest and most marginalised, especially women and older persons. Since 2015, a national ID card has been necessary to access national services including healthcare. However, only about 70% of the adult population is covered, leaving at least 50'000 people without access. International financial institutions (such as the World Bank) are promoting the rapid digitalization in LMICs without prioritisation of sequencing (e.g. systematic birth and death registration).

These presentations were followed by some reflections on the colonial dimension of the two case-studies presented as well as a reflection on the governance contradictions. Workshop participants shared their thoughts on the need for harmonisation of standards, limitations of the European Union's regulations, and the potential for regulations through the African Union.

ROUNDTABLE DISCUSSION: WHAT CAN WE LEARN FROM EFFORTS TO ENSURE EQUITABLE ACCESS TO MEDICINES AND HEALTH TECHNOLOGIES?

SPEAKERS: *Gopakumar (Third World Network), Suerie Moon (Graduate Institute), Mike Podmore (STOPAIDS)*

CHAIR: *Dr. Manish Pant (UNDP)*

The speakers began by exploring the impacts of the Covid-19 pandemic on geographic inequalities and health technologies. They highlighted that despite great advances, access barriers and inequalities remained, for example in Covid-19 vaccine coverage. They also noted growing awareness about access to health technology as a human right, with the "nobody is safe until everybody is safe" discourse.

The speakers also found similarities between 'big tech' and 'big pharma' as two examples of corporate monopoly capitalism, noting that the pandemic both made this dynamic stronger and promoted their collaboration. Speakers also saw differences in terms of the distribution of power: while the pharmaceutical industry is a closed market concentrated in high-income countries, digital technology might be more accessible with a lower entry barrier for innovators.

The speakers discussed the need for a shift of power to LMICs and communities, and for international standards on intellectual property rights which dismantle colonisation dynamics. They advised thinking beyond access to consider who controls technology and how creation facilitates control. They explored whether multistakeholderism creates an opportunity for a rights-based approach by allowing different actors (civil society, the private sector, state-actors, etc.) to communicate and participate in decision making, or whether it legitimises the enforcement of power domination by the private sector and large influential states. The conversation ended on the possibility of thinking about alternative models for developing and sharing digital technological innovations.

PLENARY DISCUSSION: COLLECTIVE REFLECTIONS ON THE FIRST DAY

CHAIR: *Allan Maleche (KELIN)*

Participants shared their collective reflections on the need to think about collective action, the need for anticipatory thinking by the human rights community in digital health, and the need to use a decolonisation framework that critically unpacks existing systems.

Friday, 20 January 2023

KEYNOTE ADDRESS: MOLECULAR SURVEILLANCE AND THE RIGHTS OF PEOPLE LIVING WITH HIV

SPEAKER: *Edwin J. Bernard (HIV Justice)*

The speaker presented a [briefing paper](#) on the repercussions of Molecular HIV Surveillance (MHS) on the rights of people living with HIV (PLHIV). To conduct MHS, scientists rely on the results of HIV genetic sequencing tests routinely done on PLHIV (i.e. to determine whether they have a strain of HIV that is resistant to treatment). This data is stored so that it can be associated with demographic details, behavioural information, and other socio-economic characteristics. MHS is used for scientific research purposes and by health departments for surveillance (i.e. to identify clusters of HIV in near-real time, to connect people to testing and care). Given criminalization of HIV in some countries, MHS may lead to interventions by law enforcement. The use of MHS raises a range of human rights concerns relating to the lack of consent, lack of autonomy, lack of community consultation in use of MHS, privacy and data protection issues, and use of MHS in an effort to "prove" transmission without a basis in science. Thus, MHS may intensify criminalisation and stigma related to HIV. Recommendations included requiring consultation with targeted communities; demonstrating that health benefits outweigh risks in proposed use

of MHS; respect for bodily autonomy and anonymity of PLHIV; strengthening informed consent procedures; and eliminating use of MHS in criminal prosecution.

The floor was then opened for a conversation, which revolved around the role of funders in promoting MHS and the impact of the Covid-19 pandemic on MHS; the Greater/Meaningful of Involvement of People living with HIV/AIDS (GIPA/MIPA) principles formalised by the UN; and the harms linked to conflating public health and law enforcement or immigration authorities. The conversation ended with a reminder that the 'H' in 'HIV' stands for human, emphasising the need to re-centre the human dimension in data and digital governance of health.

PLENARY DISCUSSION: HUMAN RIGHTS AND DIGITAL TECHNOLOGIES IN THE PANDEMIC TREATY

CHAIRS: *Alexandrine Pirlot de Corbion (Privacy International) & Nerima Were (KELIN)*

As the workshop followed on from a previous workshop on human rights and public health emergencies at Fondation Brocher, this open discussion built on the two discussions to explore human rights and digital technologies in public health emergencies. Participants especially reflected on this in the context of negotiations for the Pandemic Accord underway during the workshop period.

Participants observed that during the COVID-19 pandemic, many mistakes from previous pandemics were repeated. For instance, it was observed that the response to the COVID-19 pandemic replicated the early years of the HIV response (e.g. travel bans, isolation, limitation of human rights, overreliance on police, poor international cooperation). Previous public health emergencies (e.g. HIV, SARS, Ebola) have made clear that civil society engagement and freedom of expression are essential to blow the whistle at an early stage of a pandemic. The restrictions on civil and political rights in China slowed action on the early outbreak of the COVID-19 epidemic. Participants viewed with concern the absence of Chinese civil society colleagues in discussions around human rights and the Pandemic Accord.

Participants stressed the importance of defining prevention to include primary care and health systems strengthening, rather than digital surveillance technologies (e.g. contact tracing). Given the previous day's discussion comparing Big Pharma and Big Tech, participants discussed the

overinfluence of the private sector in the COVID-19 response, and the challenges of addressing private sector regulation within the Pandemic Accord. Participants also discussed the need to strengthen community engagement in global health security, with the aim of building trust with the public health system. Finally, participants urged the design of digital health interventions that enhance access to healthcare with a human rights lens, with the aim of achieving Universal Health Coverage (UHC). Participants discussed the work in progress on Principle 17 of the draft principles on human rights and public health emergencies, which addresses digital surveillance. It was agreed that these two discussions should continue to be linked in the future.

ROUNDTABLE DISCUSSION: DIGITAL HEALTH AND RIGHTS - WHAT ROLE FOR DONORS?

SPEAKERS: *Mike Podmore, Allan Maleche (KELIN), Katja Roll (Joep Lange Institute) (virtual)*
CHAIR: *Sharifah Sekalala*

The panellists explored the role of Overseas Development Assistance (ODA) agencies in identifying and addressing both benefits and risks of digital transformation in public health.

Speakers identified the biggest donors in digital health as the US, Germany, Finland, Norway, and Gates Foundation, supporting digital health either through direct funding to governments and organisations, or through their support to UN agencies. These donors are still in the process of defining their mandate and sphere of influence. In general, little is funded to promote digital health literacy or to strengthen human rights safeguards in digital health governance.

Speakers saw a growing recognition from donors of the need to work on regulation and better governance, as well as to build inclusive partnerships with civil society. The Global Fund, GAVI, StopTB, and UNITAID have diverse boards with potential openings to address these issues. Additional evidence would help donors develop operational frameworks and guidance; the need for normative guidance from WHO

was emphasised. At the national level, governments should also develop their own regulatory systems for donor investment. Concerns were raised about the tendency of many countries in the Global South to be pressured to adopt laws and policies oriented towards the EU and US, and the importance of stressing localisation.

The discussion turned to challenges, noting that philanthropic funders are largely closed when it comes to inclusive priority-setting with communities; private actors play an outsize role in setting the agenda at national and global levels. In most agencies, the responsibility for digital health and human rights is divided among different departments, with a resulting confusion over who should take the lead on digital governance issues. Speakers and the workshop participants emphasised the need for more mobilisation and engagement to push the need for rights-based digital governance with donor agencies and stressed the G7, G20, and the World Health Assembly (WHA) as strategic entry points for policy engagement.

ROUNDTABLE DISCUSSION: FUTURE THINKING

SPEAKERS: *Nomtika Mjwana (GNP+), Tinashe Rufurwadzo (Y+ Global), Edwin J. Bernard (HIV Justice)*

CHAIR: *Keith Sabin (UNAIDS)*

Speakers explored the future of human rights in the digital age, and ways to direct collective efforts, including:

→ Issues of freedom of expression, and the protection of groups already subject to discrimination from online bullying and violence

→ Issues of equality in access (i.e. to tech, to infrastructure, to information), keeping in mind that inequalities in the physical space are exacerbated in the digital one

→ Issues of empowerment and digital literacy: "You cannot fight for rights you do not know you have"

→ Unravelling the links between data and power: if "data is power," as the HIV sector has shown in many ways for years, how can communities reclaim their power from digital platforms?

→ Re-centering people in numbers: "the H in HIV stands for human"

→ Other lessons from the HIV response and potential models for governance (e.g. UNAIDS, FIND).

The speakers then raised a series of open questions to reflect upon, such as: What should donor funding look like in order to compel tech to take digital rights into account? What does it mean to 'opt out' of digital technologies, and is it even possible? What does 'privacy' mean, and what needs to be in place to ensure it is respected? What are the health outcomes we want to see in 15-20 years, and what needs to be put in place for them to be realised? What are the decolonization outcomes we want to see?

The discussion ended on the advocacy strategies; how to be proactive and not reactive in digital health governance. Participants emphasised the need to expand collaboration and strengthen coordination among different actors, including by building a network of progressive networks, and formulating a vision for the future that can sustain the movement and mobilise publics towards shared goals. This joint vision should be inclusive of the diverse priorities in our various contexts.

PLENARY DISCUSSION: REFLECTIONS, ACTIONS, AND FUTURE COLLABORATIONS

CHAIR: *Meg Davis (Graduate Institute)*

In this final, collective reflection, participants started by sharing their impressions on the discussions held throughout the workshop, and particularly on what they found unexpected and surprising. Participants noted how the discussion often centred data and concerns with inclusion, quantification, subjectivity and power that are familiar from 30 years of the HIV response. Participants also noted that, in spite of important differences between each geographical context, the concerns raised were remarkably similar.

Participants then shared their ideas on joint action and future collaboration, such as investing in the mentorship of young people and making sure their engagement is meaningful; mapping networks, donors, countries, and ministries in order to target advocacy efforts; connecting with the humanitarian sector; and dedicating more work to vision-setting.

Finally, participants were invited to reflect on concrete actions to be undertaken after this meeting. Ideas included creating a listserve to continue collective learning and action; introducing the issue of digital health and rights into work on pandemic preparedness; and linking networks to disseminate findings, publish papers, and develop collective actions.

Appendix A: Workshop Agenda

THURSDAY, 19 JANUARY, 2023

TIME	TOPIC	INVITED SPEAKERS
09:00 - 09:15	**Welcome and introductions**	Sara (Meg) Davis (Graduate Institute)
09:15 - 09:30	**Opening provocation: Refreshing human rights**	New Zealand Chief Human Rights Commissioner Paul Hunt (virtual)
09:30 - 11:00	**Panel: Human rights in the digital age** ➜ What does it mean for "human rights to be at the heart of tech governance"? What diverse areas should this include? ➜ Can we advance decolonization and gender equality through the digital transformation, and if so, how? What are the real-world implications of putting human rights at the center for diverse stakeholders?	**Panellists:** Scott Campbell (OHCHR) Alexandrine Pirlot de Corbion (Privacy International) Discussant: Stefan Germann (Fondation Botnar)
11:00 – 11:15	Coffee break	

11:15 – 12:30	**Panel:** Digital health and rights **- Participatory Action Research in Bangladesh, Colombia, Ghana, Kenya and Vietnam**	**Panellists;**

Panel: Digital health and rights **- Participatory Action Research in Bangladesh, Colombia, Ghana, Kenya and Vietnam**

→ Presentation of findings and recommendations from the study of mobile phone use by young people in Ghana, Kenya, Vietnam

→ Emerging findings in the ongoing study in Bangladesh, Colombia

Transnational PAR approach - benefits and challenges, questions, lessons learned

Panellists;

Nomtika Mjwana (GNP+)

Farzana Misha (BRAC)

Javier Guerrero Castro (UniAndes)

Meg Davis

Discussant: Tigest Tamrat (WHO)

12:30 - 13:30	Group photo

Buffet lunch

13:30 - 14:15	**Panel: Data and displacement**	**Panellists:**

→ Findings from the Data and Displacement study of data-based humanitarian targeting of assistance to internally displaced persons (IDPs) in Nigeria and South Sudan

→ Discussion of research and data protection in conflicts and emergencies, in the digital age

Panellists:

Briony Jones (University of Warwick)

Patrick Eba (UNHCR)

Discussant: Monique Beerli (Graduate Institute)

14:15 - 15:00	**Roundtable discussion:**	**Speakers:**

What kind of digital empowerment do young people want?

Speakers:

Tinashe Rufurwadzo (Y+ Global)

Priscilla Addo (YHAG)

Chair: Rosanne Palmer-White (Restless Development)

15:00 - 15:30	Coffee break

15:30 -16:30	**Panel: Digital health, digital identity and data rights in East Africa** → Presentation of the study of migration of data from health apps in East Africa → Presentation of the study of digital identity and exclusion of women and older persons in Uganda	**Panellists:** Sharifah Sekalala (University of Warwick) Brian Kiira (ISER) Discussant: Julie Billaud (Graduate Institute)
16:30 - 17:15	**Roundtable discussion: What can we learn from efforts to ensure equitable access to medicines and health technologies?**	**Speakers:** Gopakumar (Third World Network) Suerie Moon (Graduate Institute) Mike Podmore (STOPAIDS) Chair: Dr. Manish Pant (UNDP)
17:15 - 17:30	**Plenary discussion: Collective reflections on the first day**	**Chair:** Allan Maleche (KELIN)
18:30 – 20:00	**Meeting dinner at Fondation Brocher**	

FRIDAY, 20 JANUARY 2023

TIME	TOPIC	INVITED SPEAKERS
09:00 – 09:30	**Keynote address:** **Molecular surveillance and the rights of people living with HIV**	Edwin J. Bernard (HIV Justice) (virtual)
09:30 – 10:30	**Plenary discussion: Human rights and digital technologies in the pandemic treaty**	Chairs: Alexandrine Pirlot de Corbion (Privacy International) and Nerima Were (KELIN)
10:30 – 11:00	Coffee break	
11:00 – 12:00	**Roundtable discussion:** **Digital health and rights - What role for donors?** ➔ What is the role of overseas development assistance (ODA) in identifying and addressing both benefits and risks of digital transformation? ➔ What is within their mandate and sphere of influence, and what falls beyond that scope?	**Speakers:** Mike Podmore (STOPAIDS) Allan Maleche (KELIN) Katja Roll (Joep Lange Institute) (virtual) **Chair:** Sharifah Sekalala
12:00 – 13:00	Lunch	
13:00 – 14:00	**Roundtable discussion:** **Future thinking** ➔ What is the future of human rights in the digital age? ➔ What can we learn from the experience of the global HIV response? ➔ Where do we go from here?	**Speakers:** Nomtika Mjwana (GNP+) Tinashe Rufurwadzo (Y+ Global) Edwin J. Bernard (HIV Justice) **Chair:** (Keith Sabin, UNAIDS)
14:00 – 14:30	**Reflections, actions, and future collaborations**	**Chair:** Meg Davis (Graduate Institute)

Appendix B: Speakers and participants

SPEAKERS
(ALPHABETICAL ORDER)

Priscilla Ama Addo (YHAG) - Priscilla Ama Addo is 21 years old and currently pursuing Communication Studies at the Ghana Institute of Journalism. Priscilla volunteers with Hope for Future Generations, a civil society organization dedicated to improving the lives of the vulnerable in society and mentoring the youth in active participation of development programs. She has participated in numerous health projects, representing the youth and is currently the President of the Young Health Advocates Ghana (YHAG), a youth-led network for young people living with HIV/AIDS in Ghana, and a Youth Leader for Health. Priscilla is passionate about being a voice for the vulnerable and aspires to continue impacting the lives of young women.

Monique J. Beerli (Graduate Institute) - Monique J. Beerli is presently the Executive Director and a Senior Research Fellow at the Geneva Graduate Institute's Global Governance Centre. Her research interests include international political sociology, global humanitarianism, data-driven governance, expertise, and international NGOs. Experimenting with a range of qualitative methods—including ethnography, archival research, and biographic interviewing—Dr Beerli's work explores power dynamics that structure and arise in connection to global governance practices of protection, lifesaving, and care. Her work has appeared in International Political Sociology, Global Governance, and International Peacekeeping. Since 2019, she is a co-editor of Political Anthropological Research on International Social Sciences (PARISS).

Edwin J. Bernard (HIV Justice) - Edwin J Bernard is the Executive Director of the HIV Justice Network. Born in the UK and now based in Amsterdam, his organisation monitors the use of the criminal law to regulate and punish people living with HIV, globally; links national, regional and international advocates and organisations together; and also produces innovative advocacy tools, such as videos and web shows. Edwin, a former journalist and blogger who has been living with HIV since 1983, is also the Global Co-ordinator of the HIV JUSTICE WORLDWIDE coalition – led by a nine-member Steering Committee and supported by over 100 civil society organisations – which campaigns to end HIV criminalisation globally.

Julie Billaud (Graduate Institute) - Julie Billaud is Associate Professor of Anthropology at the Geneva Graduate Institute. Her researches examine intersecting processes of technocratic and programmatic changes in international human rights and humanitarian organizations. Her abiding interests in this intersection have led her to focus on how emerging practices of 'accountability' and 'transparency' become bureaucratized and standardized and with what implications for the notion of 'humanity' and for 'beneficiaries' or 'victims' more specifically. She is the author of Kabul Carnival: Gender Politics in Postwar Afghanistan (2015, University of Pennsylvania Press).

Scott Campbell (OHCHR) - Scott P. Campbell is Senior Human Rights Officer of the United Nations Office of the High Commissioner for Human Rights where he leads their work on technology and human rights in the Silicon Valley area. He has served as Africa Section Chief for UN Human Rights in Geneva, responsible for the work of the UN's human rights field presences in West and Central Africa. From 2011 to 2014, he was the Representative of the United Nations High Commissioner for Human Rights in the Democratic Republic of Congo, and has spent a total of 11 years living and working in Central Africa. Prior to joining the United Nations, Mr. Campbell worked with international and local NGOs over two decades, including Human Rights Watch and the International Human Rights Law Group/Global Rights where he was responsible for programs in Latin America, Asia, Africa, and Europe. He served as a US Peace Corps volunteer in the Central African Republic from 1987-1989. A US and Irish national, Mr. Campbell holds a Master of International Affairs and a Master of Public Health from Columbia University and is fluent in English, French, and Spanish and is conversant in Lingala, Sango, and Kiswahili.

Sara (Meg) Davis (Graduate Institute) - Dr. Sara (Meg) Davis is principal investigator of a multi-country participatory action research project on digital health and human rights, and senior researcher at the Graduate Institute. From June 2023 she will be Professor of Digital Health and Rights at University of Warwick. Dr. Davis has twenty years' experience in global health and human rights as a scholar and practitioner. She earned her PhD at the University of Pennsylvania, and held postdoctoral fellowships at Yale University and UCLA. She was China researcher at Human Rights Watch, and founding executive director of Asia Catalyst. At the Global Fund to Fight AIDS, TB and Malaria, Dr. Davis led early work to operationalise the Fund's commitments on human rights. She has held visiting fellowships at New York University, Columbia University, and Fordham University. She has taught at the Geneva Centre for Humanitarian Studies, University of Alabama at Birmingham, Temple University, Yale University, and University of Pennsylvania; and has consulted for UN agencies, Global Fund Board delegations, and civil society networks.

Alexandrine Pirlot de Corbion (Privacy International) - Alexandrine is Director of Strategy at Privacy International. She manages and oversees the development and delivery of Privacy International's strategic portfolio aimed at ensuring that innovative solutions serve individual and communities and protect their dignity rather than state power and corporate interest. This portfolio explores issues of digital identity, protecting communities at risk online, the digitisation of access to economic, social and cultural rights, and the use of data and technology in immigration enforcement control and border management. Before joining PI, she worked as Network and Programmes Associate at the Platform for International Cooperation on Undocumented Migrants (PICUM). Previously, she was engaged in research and advocacy on issues relating to human rights, irregular migration, Security Sector Reform (SSR), gender, conflict management, and human security. Alexandrine graduated from the University of Birmingham with an MSc in Conflict, Security and Development following an LLM in International Law at the University of Westminster following and BA in Law with International Relations from Oxford Brookes University.

Patrick Eba (UNHCR) - Dr. Patrick Eba is the Deputy Director of the Division of International Protection at the United Nations High Commissioner for Refugees (UNHCR).

Stefan Germann (Fondation Botnar) - Stefan Germann is the CEO of Fondation Botnar, Fondation Botnar is a Swiss-based foundation which champions the use of AI and digital technology to improve the health and wellbeing of children and young people in growing urban environments. To achieve this, the foundation supports research, catalyses diverse partners, and invests in scalable solutions around the world.
Read more: www.fondationbotnar.org.

Javier Enrique Guerrero Castro (UniAndes) - Javier Enrique Guerrero Castro is a PhD in Social Studies of Science and Technology from the University of Edinburgh (UK) and MSc in Science and Technology Studies from the University of Edinburgh (UK). Interested in understanding the dynamics of participation and interactions in online social networks, datafication processes and the consequences of digital infrastructures, platforms and algorithms.

Gopakumar (Third World Network) - KM Gopakumar is the legal advisor and senior researcher with the Third World Network (TWN), New Delhi. He has more than two decades of experience in the area of global intellectual property regime and its impact on developing countries.

Paul Hunt (New Zealand Chief Human Rights Commissioner) - A national of Aotearoa and the UK, Paul Hunt studied law at Cambridge University and Waikato University. He has lived and undertaken human rights work in Europe, the Middle East, Africa, and Aotearoa. For over a decade, Paul served as an independent human rights expert for the United Nations, reporting to the UN General Assembly and UN Human Rights Council. He wrote and presented some 30 UN reports, including on the World Trade Organisation, World Bank, IMF, Guantanamo Bay, the Israel-Lebanon conflict in 2006, and numerous countries. Paul's focus was the human rights to healthcare and health protection. Between 2011 and 2013, he was senior human rights adviser to WHO Assistant Director-General Dr. Flavia Bustreo. He has published extensively on human rights and has been awarded two Honorary Doctorates in recognition of his scholarship. Paul was appointed New Zealand's Chief Human Rights Commissioner in 2019. Last year, he was awarded the Ann Dysart Distinguished Service Award by the civil society organisation Multicultural New Zealand.

Briony Jones (University of Warwick) - Dr Briony Jones is a Reader in International Development in the Politics and International Studies Department of the University of Warwick and Director of the Warwick Interdisciplinary Research Centre for International Development. She is also as Associated Researcher of swisspeace and the Geneva Centre of Humanitarian Studies and a Board Member of the Centre for Community Driven Research. Her research takes place at the intersection of International Development, Transitional Justice, and Peacebuilding. Her work focuses on reconciliation, citizenship, political agency, the politics of intervention in societies undergoing a political transition and facing a past of massive human rights violations.

Brian Alex Kiira (ISER) - Kiira Brian Alex is Program Officer at the Initiative for Social and Economic Rights (ISER), Uganda. Brian is a lawyer by training and leads ISER's work on digital identity and societal inclusion. Among his most recent publications is "Chased away and left to die: How a national security approach to Uganda's national ID has led to wholesale exclusion of women and older persons."

Allan Maleche (KELIN) - Allan Maleche is a dynamic leader, an advocate of the high court of Kenya and a human rights defender with over fifteen years of experience in law, ethics, governance, policy, health and rights, including eight years managing rights-based programmes that protect affected, marginalised and vulnerable populations. He is currently serving as the Executive Director of Kenya Legal & Ethical Issues Network on HIV & AIDS (KELIN). He sits on and co-chairs the UNAIDS Human Rights Reference group, and is a member of the International Advisory Board for the Global Health Centre of the Geneva Graduate Institute. A former Board Member of the Developing Country NGO Delegation to the Global Fund Board, he also served as a member of the Global Fund's Audit and Finance Committee, and the former Chair of the Implementers Group of the Global Fund Board.

Farzana Misha (BRAC University) - Dr. Farzana Misha is an applied economist with over 12 years of experience in impact evaluations, research coordination, and program design with a focus on social safety-nets, health, digital and financial inclusion. Her research leverages tools from economics, public health, behavioral economic theory, and impact evaluation methods to determine whether and how different interventions can improve health outcomes for marginalized populations. She has a strong experiential base and understanding of multifaceted and multisectoral development programming. She has recently been engaging in the digital health space, particularly on how digital tools can be used to provide health and financial inclusionary services among the vulnerable and hard to reach.

Nomtika Mjwana (GNP+) - Nomtika is a health advocacy & communications practitioner, with experience in HIV and sexual & reproductive justice programmes. She is currently working as a Project Manager for Digital Health Rights at the Global Network of People Living with HIV (GNP+

Suerie Moon (Graduate Institute) - Professor Suerie Moon is the Co-Director of the Global Health Centre and a Professor of Practice at the Geneva Graduate Institute. Before joining the Graduate Institute in 2016, Professor Moon was Lecturer on Global Health at the Harvard T.H. Chan School of Public Health. She was Study Director of the Harvard-LSHTM Independent Panel on the Global Response to Ebola, head of Harvard's research team on the Lancet Commission on Global Governance for Health, and co-director of the Project on Innovation and Access to Technologies for Sustainable Development at the Kennedy School of Government. She also co-founded and led the Forum on Global Governance for Health and has continued to teach and advise doctoral students as an adjunct Lecturer at the Harvard Chan School. Professor Moon has served on several expert advisory bodies and boards, including most recently as Secretary of the Board of Directors of the Drugs for Neglected Diseases initiative, WHO Fair Pricing Forum Advisory Group, Expert Advisory Group to the UN Secretary General's High-Level Panel on Access to Medicines, Proposal Review Committee of UNITAID, and US National Academies of Medicine Forum on Antimicrobial Threats. She is currently the Principal Investigator on three research projects and the recipient of a PRIMA grant from the Swiss National Science Foundation.

Rosanne Palmer-White (Restless Development) - Rosanne Palmer-White is UK & Influencing Director at Restless Development, supporting young people to take action using advocacy, campaigns and communications. She previously served the agency as Head of Policy and Practice. Over the last ten years, she has also worked in UK and global advocacy roles on issues including the Post-2015 process to agree the Sustainable Development Goals, climate change and newborn & child health. She is passionate about youth leadership and the leave no-one behind agenda.

Manish Pant (UNDP) - Dr. Manish Pant leads UNDP's work on digital health as part of the global HIV and Health unit. He headed the Health and Governance unit at UNDP India during 2015-2021, successfully leading its work on implementing the electronic vaccine intelligence network (eVIN) system that digitizes the national vaccine supply chain across all public health facilities. He also led UNDP's work on developing and implementing CoWIN – a digital platform that has over a billion people registered for vaccination in India. Dr. Pant is a medical doctor and public health professional with 20 years of experience in humanitarian and development sectors across Asia, the Pacific, and Africa. He has worked for organizations like the International Federation of the Red Cross and Red Crescent Societies and the International Diabetes Federation in various public health areas, such as immunization, maternal and child health, HIV, non-communicable diseases, health emergencies, etc.

Mike Podmore (STOPAIDS) - Mike joined STOPAIDS as Director in July 2015. He leads the STOPAIDS staff team and partners with STOPAIDS Trustees in the delivery of the STOPAIDS strategic plan, and represents STOPAIDS externally in the UK and internationally. He is a steering committee member of Action For Global Health UK and the Global Fund Advocates Network. He is a co-founding steering group member of the Digital Health and Rights Project and a co-lead (alongside GFAN and WACI health) of the ACT-A Platform for Civil Society and Community Representatives. He is a board director of WACI Health and of Stamp Out Poverty. He is also a delegation member of the Developed Country NGO Delegation on the board of the Global Fund to Fight AIDS, Tuberculosis and Malaria.

Katja Roll (Joep Lange Institute) - Katja Roll is a political scientist with global health experience from civil society, donor governments and multilateral organizations. Katja's professional roots are in civil society advocacy with the German civil society network Action against AIDS Germany which she co-led in its foundation phase. She previously was a representative of Germany in the Board of the Global Fund to Fight AIDS, Tuberculosis and Malaria and headed the policy advisory programme on Global Health Funds at the Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ). In her current work as Senior Advisor for the Joep Lange Institute Katja has a key focus on digital health. In this context, she is a member of the global start-up-team of the International Digital Health & AI Research Collaborative (I-DAIR). Under the umbrella of Transform Health she coordinated a multistakeholder process to develop a Conceptual Framework to guide investments towards health for all in the digital age. This global report was launched in October 2022.

Tinashe Rufurwadzo (Y+ Global) - Tinashe is a published author, public health and communication for development practitioner with extensive experience in senior programme management, advocacy, research, generation of evidence-based guidelines, and publications development on the health and rights of young people living with, most at risk of and affected by HIV in all their diversity.

Keith Sabin (UNAIDS) - Keith Sabin is a senior advisor for epidemiology with the Strategic Information to end Inequalities team of the Data for Impact Division of UNAIDS. His foci are on improving monitoring of the HIV epidemic among key populations and modelling the epidemic in concentrated epidemics.

Sharifah Sekalala (University of Warwick) - Sharifah is a Professor of Global Health Law at the University of Warwick. She is an interdisciplinary researcher whose work is at the intersection of international law, public policy and global health. Professor Sekalala is particularly focused on the role of human rights frameworks in addressing global health inequalities. Her research has focused on health crises in Sub-Saharan Africa, international financing institutions and the rise of non-communicable diseases and she has published in leading legal, international relations and public health journals. Professor Sekalala is currently the PI on a Wellcome-Trust-funded project on digital health apps in Sub-Saharan Africa.

Tigest Tamrat (WHO) - Tigest Tamrat is a Technical Officer at the World Health Organization based in Geneva, Switzerland. Her work focuses on the use of digital technologies to accelerate health system improvements and support sexual and reproductive health. Within this role, she has coordinated multisite research on the design and impact of digital tools, as well as led key WHO resources in digital health. These include the development of the WHO Guidelines on digital interventions for health system strengthening, the Classification of Digital Health Interventions, Digital Investment Implementation Guide (DIIG), mHealth Assessment and Planning for Scale (MAPS) Toolkit, a handbook on Monitoring and Evaluation of Digital Health Interventions, and the web-based Digital Health Atlas. Trained as an epidemiologist, she holds a Masters in Public Health from Columbia University.

Nerima Were (KELIN) - Nerima Were is the Deputy Executive Director at KELIN. She is also an academic, working as a tutorial fellow at the University of Nairobi where she is pursuing her PhD. She was admitted to the Bar in 2017 and was a Mandela Washington Fellow in the area of civic leadership at the Presidential Precinct, the University of Virginia, The College of William and Mary, James Monroe's Highland, James Madison's Montpellier and Thomas Jefferson's Monticello. Nerima is a member of the Feminist Legal Network hosted by the Initiative for Strategic Litigation in Africa.

ADDITIONAL PARTICIPANTS
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Tabitha Ha (STOPAIDS)

Roojin Habibi (York University)

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