STOPAIDS
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Chapter III. Science, technology and innovation and digital cooperation

Introduction: STOPAIDS, working in partnership with the Digital Health and Rights Project (DHRP)[1], welcomes that the Pact for the Future will include a chapter on science, technology and innovation and digital cooperation.

Digital technologies are rapidly transforming our world and can help us to make huge strides towards the SDGs. While they pose opportunities, digital technologies can also pose significant risks to our fundamental human rights.

We are encouraged to see that human rights will underpin work on the Global Digital Compact, with the UN Secretary-General calling for human rights as 'the foundation of an open, safe and secure digital future'. However, it is urgent that Member States adopt rights-based approaches to digital technologies to mitigate harm.

In light of this, we propose four key recommendations for Chapter III of the Pact.

The Pact must:

1. *Recognise* that '*numerous barriers exacerbate the digital divide[2]*' and therefore that Member States and other stakeholders should identify and address the intersecting inequalities that shape digital divides for communities, especially women, young people in rural areas, young people with less education, those who speak diverse local languages, persons with disabilities, and older people, when planning digital interventions.
2. *Commit* Member States to increasing digital literacy through funding initiatives that empower communities, especially young people, with the knowledge, skills and competencies needed to understand and know their rights in the digital world, be able to use apps and digital tools safely and participate in governance of digital technologies and AI.
3. *Reaffirm* the right to participation in the governance of digital technologies, particularly for groups that have historically experienced systematic discrimination such as LGBTQ+ people, people living with HIV, sex workers, and displaced persons.
4. *Commit* Member States, UN and multilateral institutions and the private sector to implementing rights-based guidance on the regulation and governance of digital technologies.

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[1] https://warwick.ac.uk/fac/cross_fac/cim/research/digital-health-rights-copy/
[2] A/74/821 Report of the Secretary General: Road map for digital cooperation: implementation of the recommendations of the High-level Panel on Digital Cooperation

Background: These recommendations are informed by our work, in collaboration with researchers, advocates and activists worldwide, that seeks to forefront lived experience and meaningfully involve marginalised and criminalised communities in decision-making spaces for digital technologies.

At present, the policy landscape is defined by actors including governments, multilateral agencies and the private sector, predominantly in high-income countries. Rarely are the voices of young people, women, LGBTQ+ people and other key populations such as people living with HIV, sex workers, and displaced persons from low- and middle-income countries included.Yet, as end users and people impacted by the use of digital technologies and artificial intelligence (AI) it is critical that policy-makers understand their experiences and perspectives.

With the DHRP, we have conducted research with young people in Bangladesh, Colombia, Ghana, Kenya and Vietnam to better understand their experiences using digital technologies for health.[3] We found that, on one hand, young people are empowered by digital technologies and use mobile phones, social media and mHealth apps to share information, connect with peers and ultimately facilitate health-seeking behaviours.

However, we also found significant inequalities in access to technologies and that many young people reported harms such as misinformation and information censorship; anxiety about phone "addiction"; verbal abuse and other threats including surveillance, data exploitation, and offline violence. These harms were especially reported by already marginalised or criminalised groups such as women, LGBTQ+ people, and sex workers.

Digital Technologies & Human Rights: Our work, with a focus on SDG3, has underscored the importance of recognising that while digital technologies pose opportunities to achieve the SDGs, they also threaten the fulfilment of fundamental rights.

Examples of rights at risk include:

- *The right to non-discrimination:*
    - Communities that are already stigmatised and criminalised are at risk of surveillance when engaging with digital or AI-driven health systems. For instance, racialised surveillance policies and practices by governments and companies, and access to digital health data by law enforcement and other security agencies, have created an environment of mistrust because of increased tracking, monitoring and surveillance of communities at risk and subject to racial discrimination.[4]
    - Racial bias is especially pertinent, for example, in the use of digital technologies during the COVID-19 response. There is a growing body of evidence indicating that pulse oximeters used to measure a patient's oxygen levels are less accurate in darker skinned patients, often leading to overestimation of oxygen level and obscuring potential diagnosis.[5]
- *The right to health:*
    - As digital technologies are being rapidly adopted in the healthcare sector, many are being left behind. Approximately 2.9 billion people remain offline, reducing their access to

[3] https://stopaids.org.uk/wp-content/uploads/2022/11/2022_11_DHRP_research_report_final-2.pdf
[4] https://www.medact.org/wp-content/uploads/2020/06/Patients-Not-Passports-Migrants-Access-to-Healthcare-During-the-Coronavirus-Crisis.pdf
https://www.nytimes.com/2020/03/18/us/coronavirus-immigrants.html
[5] https://www.nhsrho.org/wp-content/uploads/2021/03/Pulse-oximetry-racial-bias-report.pdf

services. Women and girls, as well as those living in rural areas, on low incomes and with less education, are particularly affected. These digital divides impact health outcomes, thereby continuing the cycle of health inequality.[6]
- To further this issue, in many countries, governments make access to public services, including healthcare, conditional on the provision of a national digital identity.[7] As the UN Special Rapporteur on the rights of persons in extreme poverty has shown, this has severe ramifications for those already subject to widespread and systemic discrimination who may face obstacles in registering for such an identity document, including some ethnic minorities and migrants or persons in displacement; as well as older people and those who cannot afford digital tools such as smartphones.
- *The right to privacy:*
  - The UN Special Rapporteur on the Right to Health recently noted how "the use of digital technologies, including in the context of the right to health, can entail data collection and surveillance in ways that impinge on a range of rights, including the right to privacy".[8] Yet, during the COVID-19 pandemic, governments and the private sector ignored modern data protection laws that specifically outline the special status of health data and its higher requirements for protection.[9] For example, reports of the repurposing of contact tracing apps for law enforcement goals have emerged in numerous countries.[10]

Recommendations

1. *Recognise* that '*numerous barriers exacerbate the digital divide[11]*' and therefore that Member States and other stakeholders should identify and address the intersecting inequalities that shape the digital divides for communities, especially women, young people in rural areas, young people with less education, those who speak diverse local languages, persons with disabilities, and older people, when planning digital interventions.

2. *Commit* Member States to increasing digital literacy through funding initiatives that empower communities, especially young people, with the knowledge, skills and competencies needed to understand and know their rights in the digital world, be able to use apps and digital tools safely and participate in governance of digital technologies and AI.

A key issue that this chapter of the Pact can tackle is the systemic barriers that cause digital divides. The 2021 Global Progress report highlights the urgent need to remove remaining barriers in order to enable access to healthcare for all, identifying a '*lack of access to digital health and innovative technologies*' as a key barrier.[12] Additionally, in the political declaration of the HLM on PPR (2023), decision-makers

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[6] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8300069/

[7] https://privacyinternational.org/long-read/4472/exclusion-design-how-national-id-systems-make-social-protection-inaccessible

[8] A/HRC/53/65, Para 7.

[9] Privacy International, Extraordinary powers need extraordinary protections, 20 March 2020, https://privacyinternational.org/news-analysis/3461/extraordinary-powers-need-extraordinary-protections

[10] https://theconversation.com/police-debacle-leaves-the-mcgowan-government-battling-to-rebuild-public-trust-in-the-safewa-app-162850; https://www.dw.com/en/german-police-under-fire-for-misuse-of-covid-contact-tracing-app/a-60393597; https://www.bbc.co.uk/news/world-asia-55541001

[11] A/74/821 Report of the Secretary General: Road map for digital cooperation: implementation of the recommendations of the High-level Panel on Digital Cooperation

[12] Tracking Universal Health Coverage: 2021 global monitoring report. Geneva: World Health Organization and International Bank for Reconstruction and Development / The World Bank; 2021.

recognised the need to '*foster trust in public health systems and authorities, including by increasing public health education, literacy and awareness'.*[13] The Pact must encourage Member States to take action, such as committing funding, to increase digital literacy among young people and marginalised populations and reduce inequitable access to digital technologies and thereby also the impact of lack of access on communities. This will support the fulfilment of rights including the rights to health, to privacy and to non-discrimination.

3. *Reaffirm* the right to participation in the governance of digital technologies, particularly for groups that have historically experienced systematic discrimination such as LGBTQ+ people, people living with HIV, sex workers, and displaced persons.

The right to participation is recognised in international human rights law and interconnected with the rights to take part in the conduct of public affairs, to freedom of expression and to access information, peaceful assembly and association. The Pact must commit Member States to reaffirm the right to participation, in this case, for people to be meaningfully involved in the governance of digital technologies that affect their health and rights. The WHO Global Digital Health Strategy recommends Member States should *'implement mechanisms for more effective public participation and transparency in national and international digital health decision-making processes…'.*[14] Routes to participation must be provided in all processes from the design, implementation and governance of digital technologies. This goes beyond tokenistic consultation and must include sustained, equitable and accessible engagement with these key stakeholders.

The right to participation also highlights the necessity of viewing chapters of the Pact as interconnected, as it is also critical for Chapter IV on Youth and Future Generations. Furthermore, young people are the most digitally connected, with those online and engaged the most likely to benefit, but also the most vulnerable to the risks associated with giving up their data. It is therefore essential that young people are empowered to understand and have a say in policy-making that affects their digital rights.

4. *Commit* Member States, UN and multilateral institutions and the private sector to implementing rights-based guidance on the regulation and governance of digital technologies.

To reap the benefits of digital technologies for health while safeguarding against harms, political leaders need to build and progress on commitments to address critical gaps in digital governance and accountability mechanisms that uphold human rights in the digital age.[15]

The 2023 Political Declaration on UHC commits Member States to '*Promote policies, laws and regulations to build and strengthen an interoperable and effective digital health system'.*[16] Furthermore, multiple UN resolutions include language to address the governance gap[17], as well as the WHA in the context of health[18]. For example, the former '*affirm that the same rights that people have offline must also be protected online, including the right to privacy'*[19] and acknowledge that '*...the risks to these [privacy*

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[13] https://www.un.org/pga/77/wp-content/uploads/sites/105/2023/09/PPPR-Final-Text.pdf

[14] https://who.int/docs/default-source/documents/gs4dhdaa2a9f352b0445bafbc79ca799dce4d.pdf

[15] All the resolutions on the right to privacy in the digital age are available on the OHCHR website https://www.ohchr.org/en/privacy-in-the-digital-age/international-standards

[16] https://www.un.org/pga/73/wp-content/uploads/sites/53/2019/07/FINAL-draft-UHC-Political-Declaration.pdf

[17] For example, A/HRC/RES/42/15 (see 6 (g)), A/RES/75/176 (see 7 (f), (g) and (h)) and also A/RES/73/179 (see 6 (f) and (g))

[18] '*Strengthen governance of digital health at national and international levels*', WHO Global Digital Health Strategy

[19] UNGA A_RES_75_176: The Right to Privacy in the Digital Age

and other human] rights can and should be avoided and minimised by adapting or adopting adequate regulation or other appropriate mechanisms, in accordance with applicable obligations under international human rights law'.[20]

As outlined by the UN Secretary General '*policy frameworks for the right to health need to protect the right to privacy and security in the use of digital health technologies such as biometric identification'.*[21] Guidance should apply to governments, companies, and other third parties and include measures for recourse to justice, standards for transparency, and mechanisms for accountability. At the UN level, a Digital Human Rights Advisory Mechanism should be created to support Member States to ensure a rights-based approach to governance of digital technologies.

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[20]   UNGA A_RES_75_176: The Right to Privacy in the Digital Age

[21] Report of the UNSG: Question of the realization of economic, social and cultural rights in all countries: the role of new technologies for the realization of economic, social and cultural rights