Digital Health and Rights Project & Digital Transformation for Health Lab

Recommendations on the Global Digital Compact Zero Draft

April 2024

This briefing outlines the priorities and recommendations of the Digital Health and Rights Project (DHRP) and the Digital Transformations for Health Lab (DTH-Lab) for the Global Digital Compact (GDC). The DHRP is a group of researchers, activists, and communities living with HIV who collaborate to conduct participatory action research in low- and middle-income countries, and advocate for a human rights-based approach to governance of digital technologies and artificial intelligence (AI). The DTH-Lab is a global consortium of partners working to drive implementation of The *Lancet* and *Financial Times* Commission on Governing Health Futures 2030's recommendations for value-based digital transformations for health co-created with young people. Our recommendations for the Compact result from our combined history of experience and expertise in human rights and global health and digital governance.

A key omission in the GDC Zero Draft is health. Our research has demonstrated that health is a critical sector that is impacted by, and will continue to be significantly transformed, by digital technologies and AI. Moreover, digital transformations are now widely recognised as determinants of health due to their profound direct and indirect impacts on all aspects of health and well-being. At present there is no explicit mention of health in the Zero Draft nor a comprehensive outline regarding the complementary role that the WHO can play in implementing the GDC. We urge member states to include a reference to health, as a human right and sector that is significantly impacted by digital technologies within the text. Due to the scale of potential opportunities and risks arising from digital transformations—both within health systems and society as a whole—health should be among the first sectors in which the GDC's recommendations should be implemented.

Our Recommendations:

Preamble

We propose the addition of a paragraph in the preamble that defines the scope of the Global Digital Compact. For example, outlining that the document is relevant to digital technologies, data and emerging technologies such as artificial intelligence.

5: We affirm the efforts made throughout the text towards multi-stakeholderism and participation of civil society and communities (paragraphs 5, 7a, 7d, 26c, 65). In particular we agree with, and encourage retention of paragraph 5. References to participation should be strengthened with suggested mechanisms for civil society and community engagement at both national and international level so that there are clear expectations as to how this will be operationalised.

For example in the Political Declaration on Pandemic Preparedness and Response language includes 'integrate local communities, civil society and academia, in governance processes, through transparent information sharing and inclusive processes, including formal representation to enable participation as equal stakeholders'.

Principles

7 (a): We welcome the reference to participation in the principles in paragraph 7a. This must be retained.

7 (c): We are pleased to see consistent reference to human rights throughout the Zero Draft document (for example in paragraphs 4, 7c, 7g, 20-23, 28b, 30, 33, 38a, 46, 49bii, 49c, 59). However, generic references to 'human rights' needs to be further elaborated and specified to reflect language adopted in UN GA and UN HRC resolutions and the UN Convention on the Rights of the Child and its General Comments, particularly on the right to privacy in the digital age, and on new and emerging technology and AI. We encourage member states to retain this language and commitments towards protecting human rights in the digital age.

7 (g): We are glad to see that reference to global digital accountability has been strengthened within the principles for the Global Digital Compact. This must be retained.

Commitments and Actions

Objective 1

9: We are pleased to see language on 'meaningful connectivity' as a means to ensure quality connection to the Internet. This language should be retained.

10 (d): We welcome the commitment to connect every school to the internet and recommend that this objective be extended to also connect every health facility.

10 (h): We are glad to see mention of 'structural and systemic barriers to meaningful and affordable digital connectivity' but stress that this must go beyond 'women and girls' as at-risk populations. We must also acknowledge groups such as LGBTQI+ people, the elderly, people who are disabled, sex workers, people in rural areas, and people on the move.

Objective 2

22: We support the recommendation for a UN Digital Human Rights Advisory Service.

Objective 3

20: We support this paragraph, especially reference to the UN Principles on Business and HRs.

21 (a): We recommend this paragraph focuses on international human rights law and reads: '(a) Ensure that national legislation relevant to digital technologies is compliant with international **human rights** law (All SDGs);'

21 (b): We recommend this paragraph is broadened to cover design as well as use of technologies and reads: '(b) Establish appropriate safeguards to prevent and address any adverse human rights impacts arising from the **design, development and** use of digital and emerging technologies'

23: We recommend this paragraph is broadened to cover all companies and not only digital technology companies. It should read:

'We call on:

(a) ~~Digital Technology~~ Companies and **digital technology** developers to incorporate human rights law and principles in the development, deployment and use of digital and emerging technologies, including through the application of human rights due diligence and impact assessments, including specific to children's rights, across the technology life cycle (All SDGs);

(b) ~~Digital Technology~~ Companies, **digital technology** developers and social media platforms to commit to promote, protect and respect human rights online, be accountable for violations and abuses, and provide access to effective remedy in line with the UN Guiding Principles on Business and Human Rights and other relevant frameworks (SDGs 5, 10 and 16)'

28 (c): We suggest adding reference to respect **and** human rights so this reads: 'Institutionalise regular collaboration between national online safety institutions to exchange best practices and develop shared understandings of actions to **respect and** protect **the human rights to** privacy, freedom of expression and access to information while safeguarding against harm (SDG 17);

28 (e): This paragraph should demonstrate an intersectional approach to digital divides by listing additional vulnerable groups as many, including LGBTQI+ people, the elderly, people who are disabled, sex workers, people in rural areas, and people on the move, are also at greater risk of violence.

28 (d): We recommend strengthening this paragraph so it reads: '(d) Ensure laws and regulations on the use of technology ~~and encryption~~, in areas such as surveillance, are consistent with international standards and norms on the **human rights to** privacy, freedom of expression, due process and access to information and effective recourse **and promote measures and technical solutions for strong encryption** (SDGs 10 & 16);'

29 (a): Welcome the recommendation to engage with children and youth in the design and delivery of digital technologies. This should be retained.

30: We recommend strengthening this paragraph so it reads: 'We recognize that digital and emerging technologies can facilitate the manipulation and interference of information in ways that are harmful to societies and people and create risks for **public health,** international peace and security'

32 (b): This paragraph should clarify who is meant by 'researcher' and specify the approaches to data protection to be taken.

Objective 4

33: Language on data in the text is broad and does not recognise that different categories and uses of data may require different governance solutions. For example, health data is recognised as a special category of data due to its personal and sensitive nature therefore requiring specific governance instruments that are aligned to broader data governance agreements.

We recommend strengthening the first sentence of this paragraph to read: 'We recognize that equitable and interoperable data governance is essential to advance development objectives, protect human rights and foster innovation **and to ensure that the benefits and risks emerging from data practices are shared fairly across societies. Solidarity-based data governance is an approach that helps to protect individual rights while simultaneously seeking to facilitate data uses that are likely to create significant benefits for people without posing significant risks to people or communities**.'

35: We agree with the assertion in paragraph 33 that 'The increasing collection, sharing and processing of data, including by AI systems, may amplify risks and challenge established data protection and privacy norms'. Hence we recommend that paragraph 35 is revised to address these risks and challenges, to read:

‘(b) **Adopt legislation to ensure that personal data may only be collected for specified, explicit and legitimate purposes and must be processed lawfully, fairly so that** ~~Empower~~ **individuals and groups are able to ascertain which public authorities or private individuals or bodies control or may control their personal data** ~~to participate in the processing, control and use of their personal data, including through legally mandated protections for data privacy~~, drawing on regional frameworks such as the AU Convention on Cyber Security and Personal Data Protection and the EU General Data Protection Regulation (SDGs 10 & 16);
(c) Ensure that data collection, storage and processing practices are **equitable,** transparent, secure and in full respect of international law **and that any interference with data protection must be lawful, in accordance with international human rights law, including the principles of legality, proportionality, necessity and non- discrimination** (All SDGs);’

36: We proposed a small addition to the paragraph so it reads: ‘We acknowledge that data access and benefits, **but also risks,** are currently unequally distributed’.

40 (b): References to data privacy must be strengthened throughout the text. For example paragraph 40b should be amended to include the word ‘protect’ i.e ‘Strengthen efforts to collect, analyse, **protect** and disseminate relevant, reliable and disaggregated data for better monitoring and policy-making to accelerate the achievement of the 2030 Agenda’

41: We support the recognition that cross-border data flows should respect relevant data protection and privacy norms. Hence, paragraph 42 should outline a requirement to include effective safeguards in data sharing by adding a sub-paragraph to read: ‘**(d) ensure that any cross-border transfer is subject to appropriate level of security and protection for the personal data and do not amount to or facilitate undue interference with the right to privacy’**

Objective 5

44. We recommend strengthening this paragraph to read: ‘International cooperation on AI governance **founded on equity, human rights and other common values** is urgently required…’

45: We propose that the following is included: ‘Emphasizes that human rights and fundamental freedoms must be respected, protected and promoted throughout the life cycle of artificial intelligence systems; Refrain from or cease the use of artificial intelligence systems that are impossible to operate in compliance with international human rights law or that pose undue risks to the enjoyment of human rights, especially of those who are in vulnerable situations’

46: This paragraph should be amended to include the phrase ‘**inclusive and equitable** benefit sharing’***.***

49 (d): The potential complementary role of the WHO is not outlined in the Zero Draft except for reference to its norm-setting regarding artificial intelligence (paragraph 49d). The Global Digital Compact must make clear the role of the WHO in digital and data governance and norm-setting.

Follow Up and Review

57: We are glad that young people have been identified as a key demographic that needs to be included in discussions on the design, delivery and policy-making regarding digital technologies

(paragraph 29a, 57). We request inclusion of greater detail as to how this will be operationalised, beyond the Internet Governance Forum youth networks.

59: We support reference to the role of the OHCHR.

We encourage you to take these recommendations forward as we approach negotiations for the Global Digital Compact text, and look forward to building an inclusive, rights-based Compact together.

DHRP
Digital Health & Rights Project

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