Digital health as an enabler of human rights

Waruguru Wanjau, MD/MPH & Amandeep S Gill, PhD*

A distinction is often made in human rights between civil and political rights on the one hand and social, economic and cultural rights on the other. Indeed, two of the core covenants on human rights embody this distinction.[1] In recent years, there has been a return to the unified and integrated approach of the 1948 Universal Declaration on Human Rights.[2] Notions such as human dignity and wellbeing that we intuitively grasp across cultures underpin this approach.

Digital technologies are unprecedented in their reach and applicability across domains of human activity. They can proliferate ideas quickly across the globe and empower new techno-entrepreneurs whose businesses can be akin to virtual multi-national empires with their own regulations.[3] The digital dimension of our modern lives has been amply demonstrated during the COVID-19 lockdown.

However, when it comes to human rights the initial idealism of the Internet empowering individuals and communities with information and opportunities for self-expression has been replaced in recent years by a somber reassessment. Digital technologies can equally disempower humans and undermine human agency. They can be used to subvert social and political institutions and create new forms of deception and surveillance.

In this backdrop, how best can the health community take a rights-centric approach to digital health understood broadly as the digital enabling of healthcare, health research

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[1] International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights; texts on the website of the United Nations Office of the High Commissioner for Human Rights (OHCHR).

[2] For example, judicial activism on issues such as the environment has reinforced this convergence across categories of rights.

[3] Facebook for example had more monthly active users in the second quarter of 2020 than the combined population of China and India. *Sources:* Statista.com; Internetlivestats.com.

and health promotion? How best can we reach universal health coverage (UHC) innovatively using the digital opportunity while fully respecting human rights? We propose that such an approach be built on the three pillars of *Inclusiveness*, *Agency* and *Fairness*, and that an integrated approach to the promotion and protection of all human rights be pre-mixed in the concrete.

Inclusiveness

In our thinking inclusiveness requires a comprehensive approach captured by 'leaving no one behind'. In health research, for example, inclusiveness implies that research must be more collaborative and inclusive than it is today. Designers of research projects and their principal investigators must include more researchers from the emerging geographies of innovation in Africa, Asia and Latin America. 'Solutions' cannot continue to be designed only in a few geographies and then taken to 'problems' in other geographies. OpenMRS shows the value of developing digital solutions in the areas they are targeting to serve.[4]

In healthcare and health promotion, inclusiveness implies more creative, and even disruptive, use of digital technologies to rearchitect health systems and services for universal and affordable access. In our work, we have come across an example of a simple but powerful data-driven digital platform that significantly improved institutional delivery rates for pregnant women in a remote rural district of India.[5]

Inclusiveness also embraces representativeness in datasets as well as simply being *represented* in data. COVID-19 exemplifies the importance of inclusiveness in data representation and models. As a global pandemic that required decisive policy directives and a population response, policy makers needed to be able to rely on locally relevant digital models and projections in order to make the right decisions. Locally appropriate

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[4] Muinga, N., Magare, S., Monda, J., Kamau, O., Houston, S., Fraser, H., Powell, J., English, M. and Paton, C., 2018. Implementing an open source electronic health record system in Kenyan health care facilities: case study. JMIR Medical Informatics, 6(2), p.e22.

[5] Institutional delivery of pregnant women went up from 44% to 76% within six months through the *Sankalp* Platform developed by the Centre for Digital Financial Inclusion (CDFI) for the Government of Meghalaya India. *Source: CDFI/Government of Meghalaya.*

projections were also essential as the population needed to understand how the disease was spreading and their role in reducing the spread through hygiene practices and social distancing. This issue goes beyond the current pandemic and has long term implications since the inability of decision makers, health professionals and the general population to understand health data can affect their ability to make the required decisions or access health care.

At a global policy level inclusiveness in matters digital can best be promoted by digital public goods, combinations of which can create "common rails" for innovation of inclusive digital products and services. These "common rails" need "guard rails" to prevent the opposite of inclusiveness (exclusion) from growing.

Agency

Again, the notion of human agency is not simply one of control over the use of personal data. It is about the human centeredness of digital technology development, deployment and use. In the context of AI-based front-end diagnostic tools for example, consideration must be given to the needs and working environments of health workers in the field. They should be able to modify data typologies and structures and tune the tool to the local context.[6]

From the patient's perspective, agency is about being heard and understood, and being treated with dignity and respect even when technology is mediating healthcare. In addition to UI and UX this should consider new possibilities such as intuitive and human-centric interfaces with devices and dashboards and embedding patient experiences in AI- mediated solutions.

From a global policy perspective, agency is about public health officials and policy makers in different parts of the world being able to make real choices about technology

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[6] Such a dynamic tool is envisaged in the work of the group led by Valérie d'Acremont on diagnosis and treatment of febrile conditions in children. Press release dated 4 April 2019 by the Fondation Botnar available at https://www.fondationbotnar.org/fondation-botnar-announces-a-new-partnership-with-unisante/

depending on the scope and scale of the problems they face, availability of resources, data and connectivity, concerns and societal preferences related to ethics and privacy etc.

Fairness

Fairness implies that the benefits and costs of digital health must be shared equitably. In research it implies that we must look for new and innovative ways to acknowledge contributions to outcomes fairly and transparently. The use of AI in health is currently limited to high income countries; low- and middle-income countries (LMICs) do not have the technical capacity and resources to exploit AI for economic development and growth. There are strong forces pushing LMICS towards simpler digital health solutions such as m-health. The principle of fairness in access needs to be at the heart of more complex digital health applications and not just lower tier digital health tools. Further, the democratization and global availability of health AI approaches needs to be across all components: infrastructure, algorithms and networks.

At a global level, fairness would also imply striking a balance between misuse and missed use of data. If we reject the use of data for health out of concerns and fears about misuse, we must ask ourselves what is the missed opportunity cost for those without access to quality healthcare? Seen in conjunction with the challenge of simply being represented in data outlined earlier, this calls for what we term as the '3 Ms' approach to data governance which tackles misuse, missed use and missing data in a holistic manner. Combining the 3 Ms can create the right mix of incentives to foster multi-regional and multi- institutional collaboration and innovation on data governance. Within the 3 Ms, the focus today is on misuse of data as there are legitimate fears that health data can be used to impede one's access to rights or to promote discrimination. Prioritizing missed use need not be seen, however, in opposition to preventing misuse. In fact, this integrated approach can be the incentive that encourages broader acceptance of stronger data governance in geographies outside the EU-GDPR zone.

Integrating human rights thinking into the practice of digital health

The guiding principles that embody human rights were agreed upon before the digital age. However, they remain fully relevant in the digital age and need to be considered even more earnestly.[7] The right to the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.[8] We believe that digital technologies have the potential to enhance and safeguard this fundamental human right if deployed appropriately.

For this to happen, digital health technology development has to be viewed as a global collaborative effort. Expertise and resources from around the world need to come together to build data for health architectures that leverage local data and competences, and that empower local research communities to participate in addressing the health needs of vulnerable and less-resourced populations from around the world. These local and hyper local use communities can learn from each other and aggregate data use without aggregating data through a hubs and spokes architecture. They can help build digital public goods (common rails and guard rails) for inclusiveness and maximize impact on the ground by mobilizing communities of practice. Critically, they can inform the governance of digital health globally through practice-policy feedback loops that also improve the governance of national digital infrastructures for health.

* Amandeep S Gill is the CEO/Project Director and Waruguru Wanjau is the Governance & Hubs lead for the International Digital Health & AI Research Collaborative (I-DAIR), a multi-stakeholder initiative to create a neutral trusted platform for enabling global research collaborations on digital health and AI for health, and for convening stakeholders to develop global public goods and solve problems for the inclusive, equitable and responsible deployment of data and AI for health.

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[7] Report of the United Nations Secretary-General's High-level Panel on Digital Cooperation, June 2019.

[8] Preamble of the Constitution of the World Health Organization, WHO Basic Documents, Forty-fifth edition, Supplement, October 2006.