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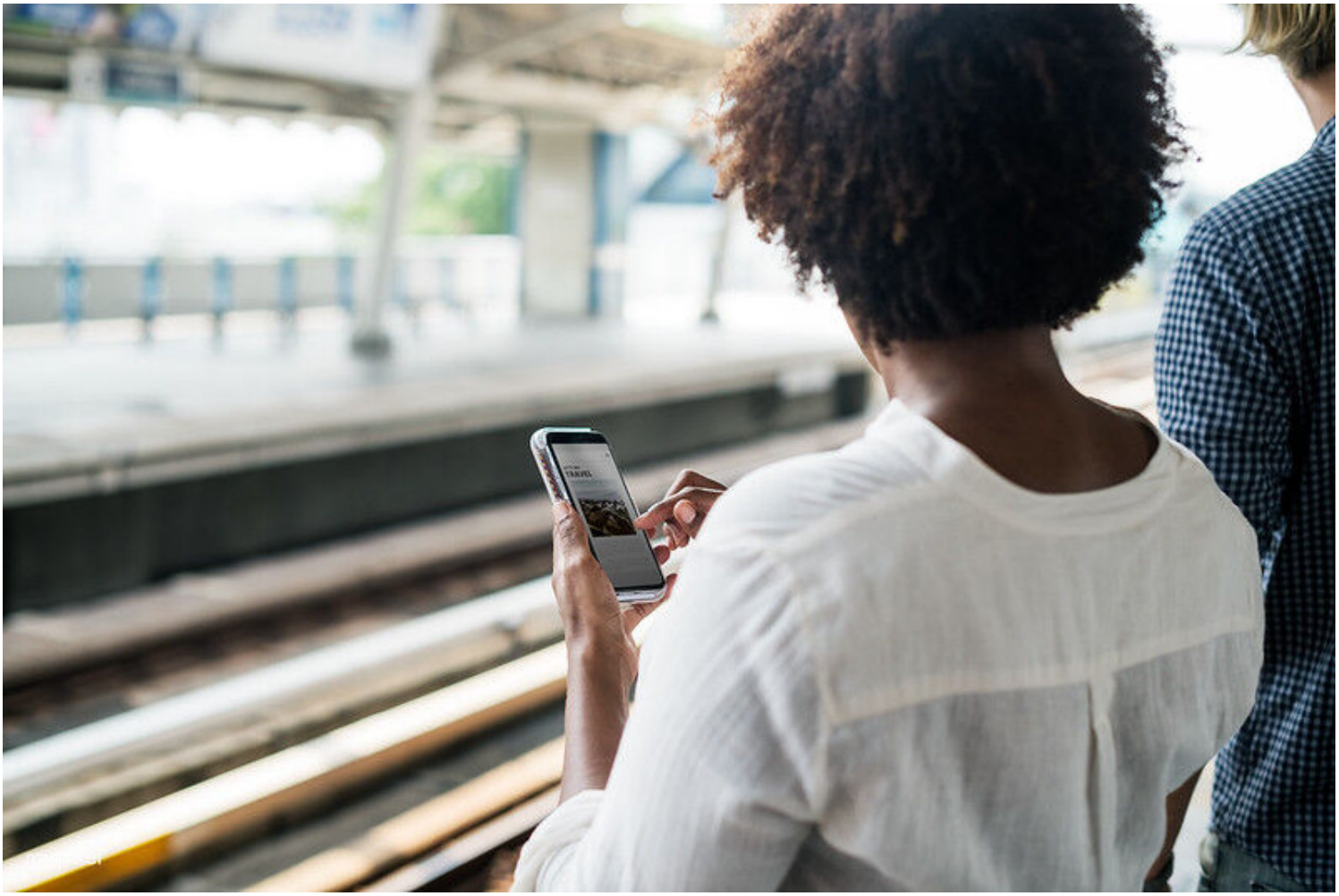
Community-level foundations to achieve UHC

A proposal for equitable health futures in a digital age

Von Nanjira Sambuli, Professor Olivia Banner

The Lancet & Financial Times Commission "Governing health futures 2030: Growing up in a digital world" (Lancet & Financial Times, 2021) explores the ways in which digital technologies and AI will impact health futures, identifying governance pathways to navigate toward improved health and well-being for young people. This short paper, authored by Commissioners Nanjira Sambuli and Olivia Banner, conceptualises equitable health futures in a digital age.



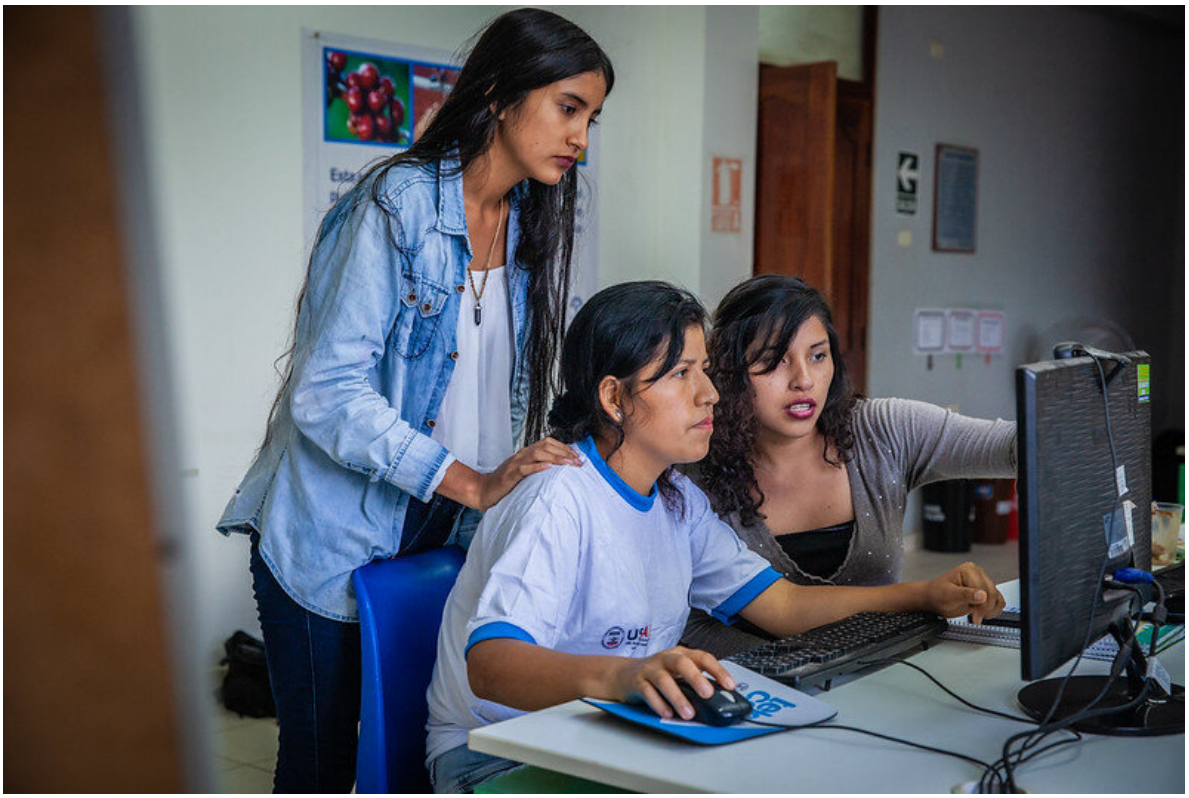
Woman waiting and playing on her phone. Photo: Rawpixel Ltd/flickr, CC BY 2.0

We are living in an Age of Digital Interdependence, when digital technologies will increasingly play a vital role in how we order our lives, our societies, our health care delivery, and our experiences of health (UN High-level Panel on Digital Cooperation, 2019). Even before COVID-19 made them so central, digital technologies' potential for improved health and healthcare dominated public discourse. These potentials have ranged from expanding virtual dissemination of health information, to individuals digitally self-monitoring their vital health indicators, to using those data along with clinical testing to generate personal health profiles for clinical consultations, and even to predicting disease outbreaks (George et al, 2019).

Covid-19 reveals barriers to accessing digital technologies

The COVID-19 pandemic further cemented the growing importance of data and digital technologies in health. The internet and connecting devices are crucial to ensuring we minimise physical contact and slow the virus' spread by working, learning, and connecting virtually. But it also brought into sharp relief the divides between those who have access — and could thus seamlessly transition to working, learning, and connecting virtually — and those who do not. It laid bare differences in access, even among the connected, in developing and developed countries alike (Martinez, 2020; MacGillis, 2020).

As 'health tech', 'digital health', 'e-health', and other variations of the digitalisation of healthcare take root, it is imperative that a systemic perspective on success factors and potential risks — going beyond the roles of particular technologies — is taken into account. Systemic analyses have revealed that digital divides —or digital dividends—can be a function of natural factors, such as geography, that render it more difficult to connect landlocked countries or archipelagos (Alliance for Affordable Internet, 2018). They can also be a function of socioeconomic factors, such as gender, education, and income (Alliance for Affordable Internet, 2016).



Digital Inclusion in the Peruvian Amazon. Photo by Jack Gordon for USAID / Digital Development Communications/flickr, CC BY 2.0

Once again, the pandemic is instructive. While technologies have been proposed as solutions to the challenges in, for example, contact tracing, this solutionism was tempered by the fact that even the seemingly ubiquitous technologies of mobile phones and Bluetooth technologies are not readily accessible to many users, nor can they necessarily facilitate the trust that human interactions between public health officials and citizens cultivate. Even tech capitals like San Francisco eventually resorted to a manual, rather than digital, contact-tracing approach in their pandemic response, illuminating the fact that building digital tools doesn't necessarily mean that people will readily trust and use the technological solution (Singh, 2020; Kissick, Setzer and Schulz, 2020; Landau, 2021).

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Core principles for sustainable, transformative, and equitable UHC

The Global Goals for Sustainable Development call for Universal Health Care (UHC) to be achieved by the end of this decade. We propose the following as prerequisites for digital technologies to succeed in supporting equitable health futures:

Infrastructure

Infrastructure must be in place to support access for all. Leaving no one behind in a digital age calls for ambitious and targeted approaches to ensuring that every individual and community is within reach of the technologies supporting these societal transformations. To harness the potential of digitalisation in achieving equitable health futures will require universal, affordable, and meaningful connectivity to the appropriate technologies— which include internet access, connecting devices, and other enabling infrastructure, such as access to energy/electrification as well as healthcare institutions.

Widespread multistakholder collaboration

Widespread support for digitalisation is also necessary, beyond those typically tasked with providing health care (through tech), that is, governments and private corporations. We also argue for a broader conceptualisation of who collaborates in digitalisation. Questions of equity and UHC often presuppose only two actors: those involved in digital health development (technical experts) and those who use the technology (patients, consumers, etc.). This field of actors should be opened up to include the workers who manufacture hardware, the assistants who input and work with data, the nurses and doctors who may exist as both care-workers and health knowledge resources, the custodians tasked with keeping infrastructure dust-free, and environmental workers who understand the limitations of resources in a currently stressed climate situation. With the entire constellation of those who have commons knowledge of health, health institutions, delivery of care, and pragmatic use of technologies, a broader field of collective knowledge makers is brought into play to ensure that digital tech is sustainable.

Community participation

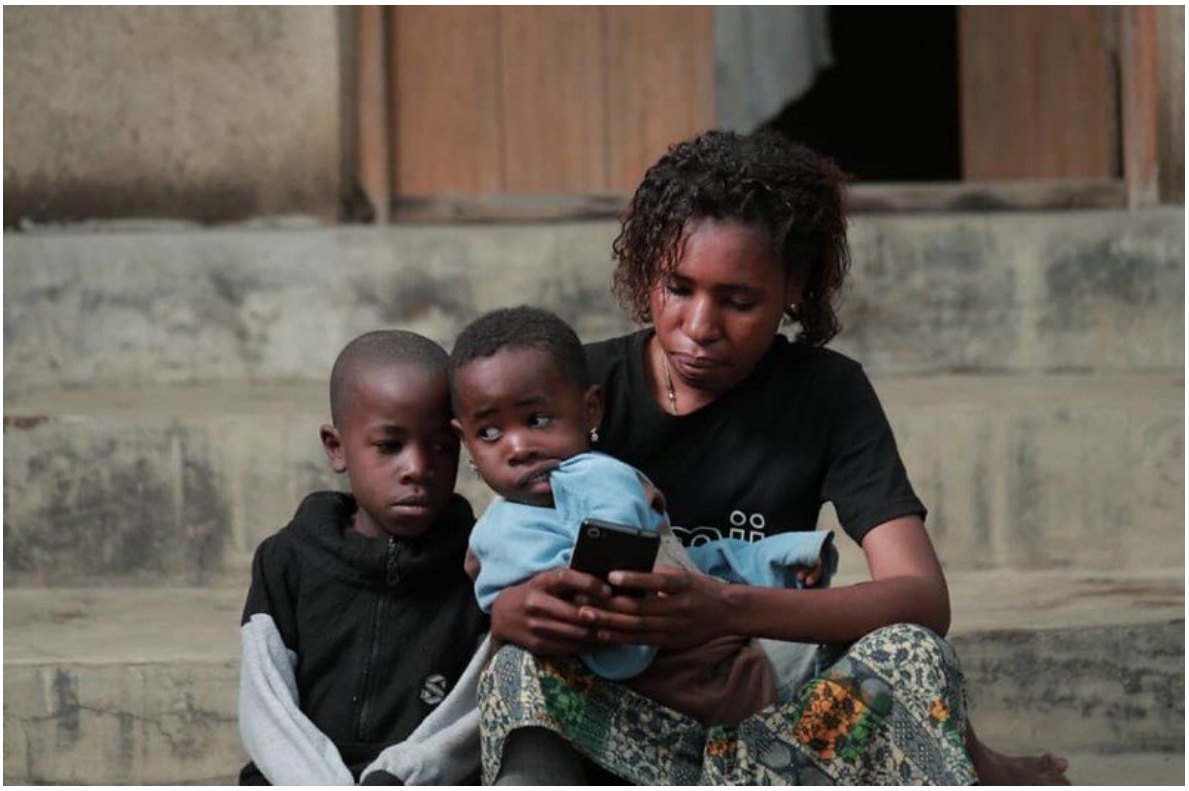
Community participation should also be reconceptualised outside of typical frameworks, such as ‘buy in’ and consultations-as-a-tick-box measures. It must embody ways in which communities (often deemed ‘beneficiaries’) become actively and continuously invested in seeing digital technologies succeed, because they have deliberated over design and implementation, potential for harms, and appropriate forms for technologies introduced to be sustainable within respective communities.

In other words, digital tech succeeds where citizens (and noncitizens) are affirmed in their “commons knowledge,” where knowledge is socially situated and grows out of forms of relationality, rather than transactionality (Irani, 2019; Kelty, 2020). For example, as part of a successful community pandemic response in the U.S., contract tracers in the Fort Apache Indian Reservation used their understanding of their communities’ travel patterns to create targeted interventions to stop the virus’ spread (Landau, 2021); in South Korea, digital and non-digital responses — which drew from knowledge about previous epidemics and the state of digital connectivity and accessibility in the country — fostered community trust and cooperation and jointly contributed to the nation’s pandemic mitigation strategies (Landau, 2021). Communities working creatively, democratically, and deliberatively to assess, evaluate,

and build through and with digital technologies are best equipped to debate and discover the best forms that digitalisations can take to promote their lives and health. Another way to put this is that, in an age when expertise and authority are facing a trust deficit, cultivating solidarity is key to ensuring digital technologies help us achieve UHC.

Governance mechanisms

Additionally, people must participate in the creation of governance mechanisms, including in digitalisations. Such mechanisms should not only "support" design by and the decisions of technical experts and government regulators; they must be fully integrated with institutional and corporate decision-making capacities and be the first, rather than the last, level of evaluation of digital tech, whether in relation to auditing bias in AI, assessing sustainability, or deciding on the desirability of individual and system-wide health technology integration. Governance models must be in place that allow the community to decide how, when, and where data extraction, circulation, sharing, and analysis is appropriate.



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A rights-based framework

Strongly linked to this is the importance of rights-based frameworks. While most legislative instruments prioritise individual rights, the digital health research ecology draws insights not only from individuals' data, but also from combining datasets. In this paradigm, the violation of an individual's right to privacy, for instance, is also a violation of the privacy of a collection of individuals, for example, when individuals have been sorted into groups through digital tools like algorithms (Tisné, 2020). Thus, other frameworks for rights must be considered, especially those of collective or group rights, as we bolster the rights norms and frameworks to accommodate digitalisation.

Communities must be able to decide whether or not digital technologies, including AI and machine learning, are the best solution for their health needs, if they are even an appropriate solution. They should be able to refuse those proposed solutions without such refusal translating into being excluded from health care (Cifor et al, 2019). It is critical to factor in that what is scalable from a 'top-down' level may not be sustainable at a community level. The economic imperative to scale up is not always feasible for sustainability, nor does it honour a particular community's local knowledge, and it should be eschewed if the goal is to garner trust and participation (Arora, 2010)

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Disability-led design and intersectional feminist principles

Furthermore, we advocate for disability-led design principles to undergird digitalisation design practices. Traditionally, designers consider disabled people as people to be designed *for* rather than *with*, and disability is treated as a site of technological innovation.In disability-led design, disabled people are centred as innovators themselves, and they serve as the leaders in new designs, not as merely end-stage usability testers (Jackson, 2018). We also advocate for intersectional feminist principles, which place those who are most oppressed, under-resourced, or otherwise at the bottom of social hierarchies at the centre to strive for design that advances participation among all, not only those most resourced, to contribute (Costanza-Chock, 2020). These two principles — in addition to more established Principles for Digital Development — can encourage solidarities around digital health (Principles for Digital Development, 2017).

Toward equitable health futures

The above are recommendations for establishing sound, community-level foundations to guarantee that digital technologies positively contribute to equitable health futures. As with climate change, the digital divide, infrastructure emergencies, social and global inequalities, and other emergent complexities, the future is already here, it's just not evenly distributed. Digital technologies can be transformative and work to redistribute structural health inequality towards equitable health futures. But, to do so, they must foster community participation to ensure they do not intensify existing inequalities.

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