Growing up 2030 in a digital world

GOVERNING HEALTH FUTURES
THE LANCET & FINANCIAL TIMES COMMISSION

Meaningful youth engagement and inclusion in digital health governance

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KEY MESSAGE

There are unique risks and opportunities for children and young people amidst digital transformations, and as such it is important to engage and include these groups in digital health governance. Not all practices for engaging and including youth necessarily result in meaningful engagement where youth have ownership and agency. Creating meaningful youth engagement in digital health governance demands that stakeholders be continuously introspective on the dynamics of power throughout the process of working for and with youth.

The importance of engaging and including youth in digital health governance

The Governing Health Futures 2030 Commission has a particular focus on children and young people (including youth). Today's youth population is the largest in human history—1.8 billion people are between the ages of 10 and 24.[1] While 48 per cent of the overall population is digitally connected, nearly 70 per cent of youth are digitally connected, with an estimated one in three internet users under the age of 18 years.[1,2]

Although connected, children and young people experience opportunities as well as risks in digital environments. First, youth often lack digital literacy and skills to protect themselves from online harms, predatory marketing and data extraction practices, infringements on consent, and other rights violations.[3] Thus, as children and young people are more likely to be online, not only is their exposure to digital environments increased but also their exposure to subsequent harms within such environments.[4] Secondly, children and young people who are digitally disconnected often experience further harms which can translate to material and social deprivations including but not limited to reduced access to education, job opportunities, healthcare, and social environments for mental health and well-being.[5] Lastly, beyond the unique risks posed to children and young people amidst digital transformations, youth also experience and contribute many benefits, including the ways in which they innovate and mobilise technologies to strengthen the health workforce.[6]

Given these risks and opportunities which impact health futures, children and young people whose health futures are in the balance must be explicitly and intentionally considered as partners and drivers in shaping mechanisms for digital health governance.

1   International Telecommunications Union. ICT facts and figures 2017. Geneva: International Telecommunication Union; 2017.

2   Livingstone S, Carr J, Byrne J. One in three: internet governance and children's rights. Florence: United Nations Children's Fund; 2016.

3   UNICEF. The state of the world's children 2017: Children in a digital world. New York: United Nations Children's Fund; 2017.

4   Holly L, Wong BLH, Agrawal A, Awah I, Azelmat M, Kickbusch I, et al. Opportunities and threats for adolescent well-being provided by digital transformations. PMNCH background paper. Geneva: Partnership for Maternal, Newborn and Child Health; 2021.

5   UNICEF and ITU. How many children and youth have internet access at home? Estimating digital connectivity during the COVID-19 pandemic. New York: United Nations' Children Fund, 2020.

6   Wong BLH, Khurana MP, Smith RD, El-Omrani O, Pold E, Pold A, et al. Harnessing the digital potential of the next generation of health professionals. *Hum Resour Health* 19, 50 (2021).

However, due to the rapid pace of change of digital transformations in health, youth's risks and opportunities often either fall beyond the scope of traditional health governance or are not easily identified by non-youth individuals in positions of power. Not only does this highlight the importance of engaging and including youth in the governance of digital health, but also begs the question "how can current mechanisms of youth engagement be improved so they are truly meaningful?".

Current practices of youth engagement and inclusion

In recognition of the need to engage and include youth in digital health governance, organisations such as the World Health Organization, AMREF, and the United Nations (through The Secretary-General's Envoy on Youth) have recently published guidelines on youth engagement and are increasingly engaging and including youth in their activities.[7,8] Across organisational guidelines and activities, four mechanisms to engage and include youth are frequently presented: co-design, co-creation, youth boards and participatory research. The Youth and Media (YaM) team at the Berkman Klein Center for Internet & Society at Harvard University have also shared insights on ways that different stakeholders such as international organisations, companies, researchers, and educators can build participation models which enable meaningful youth engagement in our increasingly digital world.[9]

Striving for meaningful youth engagement and inclusion

Meaningful youth engagement and inclusion involves accessible and ongoing mechanisms whereby youth can play a part in decision-making processes that affect their lives, including the design, development, implementation, and evaluation of all policies, programmes, services, and tools related to digital technologies, data, and health. Meaningful engagement entails decision-makers not just listening to the voices of youth but also reporting back to youth on how their perspectives were taken into consideration.

Despite efforts to scale up youth engagement and inclusion, youth consulted by the Commission expressed scepticism about the degree to which current practices of youth engagement and inclusion in (digital) health governance are indeed meaningful. Youth who have been 'engaged' and 'included' have critiqued how processes for their engagement and inclusion have not only tokenised youth through their symbolic inclusion but also museumised youth by providing them with spaces to voice their needs and recommendations without accountability mechanisms for how these will be acted upon.

To address this, youth have demanded that they not be ostracised to their own organisational sub-structures. Youth have made clear the benefits of their engagement to those in positions of power, thinking of strategies of youth engagement and inclusion beyond so-called innovation. Youth have recognised there is a lack of political will to establish accountability mechanisms to address their perspectives (in part because they are often incommensurable with political and economic agendas) and have therefore called for organisations to not only think more strategically about how to fund youth activities but also make the political choice

7   WHO, UNFPA, UNICEF, UNESCO. Youth-centred digital health interventions: A framework for planning, developing, and implementing solutions with and for young people. Geneva: World Health Organization; 2020.

8   Amref Health Africa. One Amref for youth statement. Nairobi: Amref Health Africa; 2021.

9   Cortesi S, Hasse A, Gasser U. Youth participation in a digital world: Designing and implementing spaces, programs, and methodologies. Harvard: Youth and Media, Berkman Klein Center for Internet & Society; 2021.
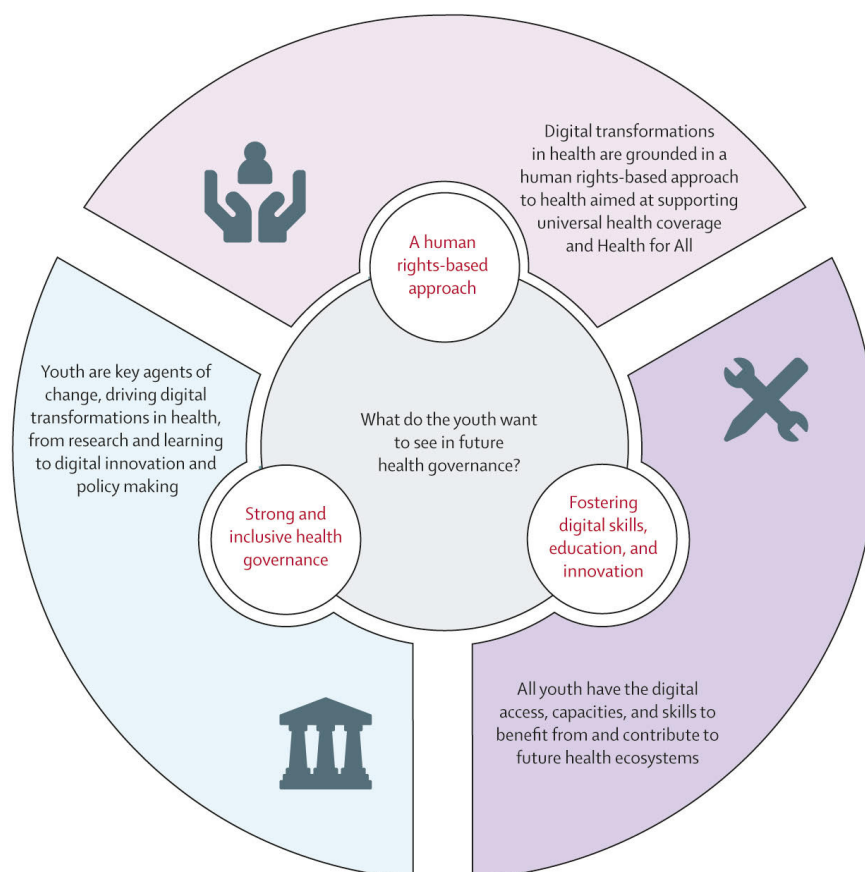
to do so.[10,11] Ultimately, it is important for stakeholders engaging and including youth to be continuously introspective regarding the dynamics of power throughout the processes of working for and with youth.

As part of the Commission's youth engagement mandate, it held a two-part youth consultation in which youth discussed how they identified as a group, their main concerns and proposed solutions with respect to the digital transformations in health, and the health futures they want.

The culmination of these discussions resulted in the co-creation of a Youth Statement and Call for Action directed at digital health governance stakeholders (including policymakers) to complement the Commission's report.[12]

Youth underscored three key aspects youth that they want to see in the future of health governance: a human rights-based approach; strong and inclusive governance mechanisms; and the fostering of digital skills, education, and innovation (see figure 1).

Figure 1. Summary of the results of the Governing Health Futures 2030 youth consultations

Digital transformations in health are grounded in a human rights-based approach to health aimed at supporting universal health coverage and Health for All

A human rights-based approach

Youth are key agents of change, driving digital transformations in health, from research and learning to digital innovation and policy making

What do the youth want to see in future health governance?

Strong and inclusive health governance

Fostering digital skills, education, and innovation

All youth have the digital access, capacities, and skills to benefit from and contribute to future health ecosystems

10 Wong BLH, Smith RD, Siepmann I, Hasse A, Tandon S. Youth engagement in digital health: a critical perspective towards meaningful youth agency in governance. MMS Bulletin 157; 2021.

11 Budiono N, How can we leave behind tokenistic approaches of engagement to make way for meaningful ones? MMS Bulletin 157: 2021.

12 Governing Health Futures 2030 Commission. Youth statement and call for action. Geneva; 2021.

Implications for policymakers

All national and local governments should enfranchise communities and advance public participation in the codesign and implementation of digital health policy and technology. In this regard, policymakers should consider youth as a unique demographic that demands particular attention. The reasons for meaningfully engaging and including youth in digital health governance—to mitigate their risks beyond the perspectives of governance and benefit from their unique skill sets—are various. Furthermore, policymakers should consider strategies to strive for meaningful and continuous youth engagement and encourage non-government stakeholders to also practice meaningful youth engagement. The novelty of these policy implications indicates that further work is needed with youth partners to ensure successful policy implementation. Specifically, this can be done in the areas where youth have unique needs to those that exist within the traditional scope of digital health governance. Additionally, further understanding is needed regarding the effectiveness and impacts of various forms of meaningful youth engagement, as determined by youth themselves, that may take across different organisational contexts and dynamics of power.

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