Meaningful youth engagement and inclusion in digital health governance

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**KEY MESSAGE**

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**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. 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.

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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

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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. 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


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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