



Wilton Park



Image: The Lancet & Financial Times Commission

Report

Governing Health Futures 2030 Youth Consultation: What do youth want to see in the future of health governance

Wednesday 20, Thursday 21 January 2021 | WP1882

In partnership with:





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In partnership with the Lancet and Financial Times Commission Governing health futures 2030: Growing up in a digital world

Introduction

For the first time, a joint The Lancet & Financial Times Commission entitled Governing health futures 2030: Growing up in a digital world (GHFutures2030) is exploring the convergence of digital health, artificial intelligence (AI), and other frontier technologies with universal health coverage (UHC) to support attainment of the third Sustainable Development Goal (SDG): Ensuring healthy lives and promoting wellbeing for all at all ages.

Youth are identified as requiring particular attention to ensure that no one is left behind in the achievement of UHC and SDG 3. In 2030, the global population will be 8.55 billion, of which 3.3 billion (39%) will be under 25 and 2.03 billion (24%) will be under 15. Therefore, one of the objectives of The Commission is to strive for integrated digital development that improves the health and wellbeing of youth in an ever more digital world.

For that reason, The Commission is committed to engaging youth from around the world in its deliberations. This meeting was the first in a series of two events designed to encourage youth internationally to participate in and contribute to a dialogue about what it means to grow up in a digital world and what they want to see in the future of health governance.

Aligning with its Youth Engagement Strategy 2020 – 2023, The Commission aims to collaborate with a broad range of youth networks to develop a Youth Statement and Youth Call to Action to inform the final report, scheduled to launch by the end of 2021, as well as to guide advocacy and dissemination activities following the launch of the report.

Summary

What does it mean to grow up in a digital world? What does digital transformation actually mean for health and health systems? What will health systems and universal health coverage look like in 2030 for youth, and how will digitalisation actually make a difference? What roles should youth play to support the development of digital health systems? These are some of the key questions that youth participants from the meeting discussed during the meeting. The Commission encouraged all youth present to be challenging and creative, and to develop statements about values, governance, and solidarity for public health good including any concrete recommendations for stakeholders that start to emerge. The youth statement will accompany the main Commission report, and both are instruments for advocacy.

“The ultimate goal is that we want to bring health closer to the people and create better health systems”

“You don’t have to do everything all by yourself. If we can bring together different youth actors we can work together and create something together”

“Technology must be a tool to reduce gaps and not a gap by itself”

“We need more youths sharing about ways to keep moving forward without leaving anyone behind, whether through a coalition or a regular platform for us to keep sharing ideas and best practices.”

Key points

- While many youth are the first to grow up super-connected to the Internet, many countries with the most youthful populations in the world face a double disadvantage of inequality and low access to technology.
- Health outcomes are poorer when there are barriers to accessing equitable health services including digital services.
- Youth globally need to be supported to access the Internet or to find other digital health solutions; not only physical access but access to accurate information.
- Youth constituencies around the world need to be linked so learning and experiences of digital health can be shared at global, regional and country levels.
- Youth can identify their priority health needs, which differ across the world; disaggregated data infrastructures can guide priorities and advance health equity.
- Youth often lack digital awareness so increasing literacy through training and education for youth is vital, especially in response to data rights, and harm recognition and reduction.
- Innovation is needed to build a dynamic and participatory digital health infrastructure that reflects the realities of youth.
- Laws and regulations are crucial for companies to follow and for accountability, but given realistic expectations of what might change, it is vital for youth to learn to practice their digital identities in a more holistic and educated manner.
- Online terms and conditions seeking consent could be made easier for youth to understand so consent is better informed; however opting out is difficult when youths then miss out.
- Health systems and health priorities differ according to location, and interoperability is key. Digital health systems must be locally relevant but internationally networked.
- Digital health must put human and youth’s needs at the centre of the design; ensuring a balance between digital convenience and need for human interaction.
- A human rights approach is needed to ensure that digital health is accessible to everyone, and that no one is left behind.
- Youth need to step forward and create youth-minded and youth-centric solutions; young digital entrepreneurs can change the status quo and disrupt the system.

Summary of emerging recommendations

- i. Map national and international youth organisations so we know where they are and can better understand how to mobilise a greater youth digital health movement.
- ii. Build and invest in strong youth community networks, so youth can advocate for themselves.
- iii. Conduct youth-centred research, particularly in health and digital health programmes for youth.
- iv. Create a guide to resources for youths interested in being a digital health advocate.
- v. Undertake process mapping on which individuals and organisations or entities bear responsibilities for behaviour around data privacy and use.
- vi. Create guidance about whose responsibility it is to educate youth to build digital

- literacy, and which areas should be the focus of attention.
- vii. Make computer studies mandatory at a young age including education about data, data rights and engaging safely and effectively in the technological world.
 - viii. Involve youth in designing frameworks and educational resources to improve digital health literacy.
 - ix. Conduct work from an evidence-based approach, which requires detailed landscape analysis of what the problem is before starting to build digital systems in response.
 - x. Stimulate and support young entrepreneurship in digital health.
 - xi. Support the establishment of a youth coalition or regular platform for continuous exchange of ideas and practices.
 - xii. Young leaders should collectively champion human-rights-based digital health care.

The equity and participation gap

1. While there is increasing digitalisation globally, some countries have been left behind. In some places, this digital generation under 25 is the first in history to have grown up super-connected since birth. But many countries with the most youthful populations in the world are facing a double disadvantage of inequality and low access to technology.
2. Participants discussed these core issues of inequity, and how to overcome the glaring gaps in connectivity and participation. They recognised that life quality and health outcomes are poorer when there are barriers to accessing equitable health services, including digital services. Some key points they raised included:
3. **Connectivity:** For many youths around the world the cost of Internet connectivity is prohibitively high; so it is important to either provide financial support or spaces for youth to connect to the Internet, or find other digital health solutions such as using SMS. In some places, applications with low bandwidth are necessary, and it is important for youth to understand what technologies are needed to in order to engage. It is crucial for any health messages in the digital space to be evidence-based and verified, so the issue is not just about having access, it is also about having access to the right information.
4. **Digital ecosystems and spaces:** A lack of equity exists in the tools and quality of care available particularly within a given digital eco-system or device, and proprietary systems and algorithms can perpetuate exclusion and inequities.
5. **Youth participation:** It is vital to engage youth in the design, implementation and evaluation of all digital health interventions. The timing and method of participation needs to be flexible for all youth. Youth's contributions must be valued, recognised and remunerated.
6. **Linking youth constituencies:** There is a need to create a cascading effect to reach out to and link youth constituencies so youth can share and learn together at global, regional and country levels. While youth need devices and connectivity, they also need spaces that embrace equity, rights and participation. Digital spaces provide opportunities to connect but they can also perpetuate structural inequalities, so how spaces are created is very important.
7. **Youth community building:** Youths need support in capacity building, education and empowerment. It is vital to identify and provided needed resources for those youths who struggle with access.

“I would love to know what worked in different parts of the world. Perhaps the answers we need have already been done elsewhere”

“When digital health solutions are designed, efforts should engage and empower diverse youth groups.”

Emerging recommendations:

- Map national and international youth organisations so we know where they are and can better understand how to mobilise a greater youth digital health movement.
- Build and invest in strong youth community networks, so youth can advocate for themselves.
- Conduct youth-centred research, particularly in health and digital health programmes for youth.
- Create a guide to resources for youth interested in being a digital health care advocate.

The choices we have

8. As the complex world of digital health unfolds, what choices do youth have to make in order shape their future? Participants considered realistic choices to make and solutions to be found in terms of priority health needs for youth, education and social norms being established around digital health, and issues around digital identity, privacy and data ownership.
9. **Priority health needs:** Globally, the priority health needs of youth include malaria, asthma, sexual and reproductive health and mental health. In some countries, meeting the basic needs of food, shelter and water is still an issue. However for youth in other parts of the world, being able to interact with health care virtually was important. Autonomy and the right to decide, access to information, gender sensitivity, and the digital environment as a safe space were also raised as priorities. Disaggregated data infrastructures can guide priorities and help advance health equity.
10. **Digital awareness and literacy:** Participants emphasised the lack of digital awareness and literacy among youth, especially around data protection and privacy issues. Literacy can be low, depending on experience, and greater awareness and response to harm recognition, reduction and education is required.
11. Aspects of digital identity that youth need to practise in a knowledgeable manner include data privacy, autonomy, community and vocalisation of ideas. It is also important to set localised social norms and etiquette on how youth can engage in online spaces.
12. Therefore, training and education for youth is critical. Curriculum should support youth to obtain skills around sharing data securely, and real life digital experience such as understanding the language of terms and conditions. Computer studies should be mandatory at a young age, with education about data, data rights and engaging effectively in the technological world.
13. **Balance of regulation versus education:** While training and education is a necessary component of safe and effective digital spaces, laws and regulations for companies and the private sector to follow are also crucial for more control and accountability over data. Regulation is needed not just for protection to prevent access to data, but strategies and laws to prevent the ability of anyone to use data against individuals.
14. The idea of a global treaty or global etiquette emerged. However, increased regulation of companies cannot be assumed in a world driven by profit. In this case, more literacy is required along with deeper understanding and action for those who bear responsibility for data.
15. **Mapping responsibilities:** It is important to undertake process mapping on which individuals and organisations or entities bear responsibilities for data privacy and use. On the one hand, increased digital literacy is critical for youth so they fully understand

“If we believe our data is being misused, we should have recourse to seek action.”

their options and consent to what they do in an informed manner. However, decoding and making complex terms and conditions more easily understandable to youth, so they can take informed decisions, would be an action that companies could take. Guidance, educational resources and frameworks should be co-designed with youth in order to increase understanding.

“Digital transformation should do no harm. How do we protect youth from harms?”

16. **Consent:** Consent is a key issue for youth and participants discussed the ‘consent culture’ when it comes to data use, and the choice to opt in or out and what might mean. Participants discussed informed voluntary consent, with options and alternatives so that data and user autonomy are safeguarded. Participants felt the need to have more control over their data, as individuals should own the data and there should be transparency in how it is used; yet there is a conundrum as they still want to use those platforms that ask them to relinquish that control. How therefore to encourage companies to let go of data access? In a digital environment driven by profit, this was considered unrealistic.

“I wish we could begin with educating people before creating tools.”

Emerging recommendations

- Undertake process mapping on which individuals and organisations or entities bear responsibilities for behaviour around data privacy and use.
- Create guidance about whose responsibility it is to educate youth to build digital literacy, and which areas should be the focus of attention.
- Make computer studies mandatory at a young age including education about data, data rights and engaging safely and effectively in the technological world.
- Involve youth in designing frameworks and educational resources to improve digital health literacy.

“Perhaps, this is an opportunity for young leaders to collectively champion human-rights based digital health care.”

The future we want

17. As youth face the future, what can be envisaged for digital technology and artificial intelligence (AI) in relation to priority health needs? What kinds of digital health systems could be developed and implemented and what is the role and potential of youth to help create and shape them?
18. **Innovation:** Innovation is required to build a dynamic and participatory digital health infrastructure which users can refine and improve digital health services to fit their own needs. This infrastructure needs to reflect the realities of youth and intersectional users in digital health services and platforms, which means engaging and including youth in design, implementation and evaluation in innovative ways. Data autonomy and ethics need to take centre stage in the digital platforms created. Education on digital health is needed in schools, specifically about ethics and safety.
19. **Interoperability:** Different parts of the world have different environments and needs, therefore localised public health and digital health approaches are required. No one size fits all, as health systems and health priorities differ according to location. If people move from one country to another, there should be some basic level of similarity in usage of digital health, and interoperability is key. Systems must be locally relevant but internationally networked. Approaches should demonstrate flexibility and allow room for growth. Think about how established health systems are in a given country – no one size fits all approach.
20. **Human-centred design:** With AI becoming increasingly available as a digital health interface, particularly seen during COVID-19, is there a need for increased personalisation and human connections and a balance between digital convenience and human interaction? This is particularly the case in relation to mental health; for example, there are practical and ethical implications for patients talking to an AI mental health chatbot versus a human therapist. Do we want humanised AI or should the distinction be maintained? Will trust be eroded if people do not know they are

“The kind of movement that we promote as youth should be aligned with our goals of leaving no one behind.”

talking to an AI agent or not?

“Are we discussing what is needed for the most in need? Very poor regions still lack access to the basics.”

“For our dreams and future, health is a priority.”

“We need to start from an evidence-based perspective, coupled with education and literacy.”

21. It is important for digital health to have human and youth needs at the centre of the design. It should be free from discrimination and accessible in terms of faces, places and accents to all youth. Language should be culturally relevant and youth sensitive, and care should be holistic including physical, mental and spiritual.
22. **Equity and human rights:** Attempts to create an equitable global digital health system do not start from a level playing field. Different countries have different levels of access; half the world’s population is not connected and not everyone who is connected is well connected. Even in countries with good connectivity, not all the population is digitally literate and able to use the Internet effectively.
23. A human-rights-based approach to the conversation is needed to ensure that digital health will be accessible to everyone, whether locally or internationally. It raises the question of how it can be designed to fit everyone’s needs and how everyone can benefit around the globe, including those youths who are often marginalised such as homeless people, migrants and refugees. When building digital health systems, a human rights framework must be established which really promotes health for all and leaves no one behind.
24. Could a convention on digital human rights highlight the interplay and balance of local capacity versus international capacity, taking into consideration the need to avoid international domination and appreciate different cultural and societal norms?
25. **Roles for youth:** the role of young digital health entrepreneurs is to change the status quo of the system, and disrupt it. Youth need to step forward and create youth-minded and youth-centric solutions in the health sector. Young entrepreneurs do not need to be in the health sector to construct paths forward, but international collaboration is key so that all youth constituencies have an opportunity to contribute and build a better digital health infrastructure.

Emerging recommendations

- Conduct work from an evidence-based approach, which requires detailed landscape analysis of what the problem is before starting to build digital systems in response.
- Stimulate and support young entrepreneurship in digital health.
- Support the establishment of a youth coalition or regular platform for continuous exchange of ideas and practices.
- Young leaders should collectively champion human-rights-based digital health care.

Conclusion

This first Wilton Park meeting in a series of two was an opportunity for youth around the world to begin to identify their priority health concerns, and to chart a way forward for their engagement with building a digital health future. The discussion will contribute to the final report from the Commission, and to the Youth Statement that will accompany the report. It is a timely opportunity to stimulate advocacy and stakeholder action to support youth recommendations in the area of digital health futures. The summary of recommendations emerged during the discussions and will help inform future conversations, in order to firm up a full set of recommendations and the final Youth Statement.

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