



Wilton Park



Report

Governing health futures: youth consultation on the principles of health data governance

Wednesday 14 July 2021 | WP1959V

In association with: Transform Health, YET4H and The Lancet & Financial Times Commission Governing health futures 2030: Growing up in a digital world (GHFutures2030)





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Background

The Lancet & Financial Times Commission Governing Health Futures 2030: Growing up in a digital world (the Commission) is charged with developing a vision for stronger governance of digital health technologies and data, with emphasis on harnessing their contribution to achieving Universal Health Coverage (UHC) and improving health and well-being for children and young people.

In partnership with Transform Health, Young Experts Tech 4 Health (YET4H), and the Commission, Wilton Park hosted a consultation with Commissioners and other global thought leaders and experts to review the draft Health Data governance Principles (hereafter: 'Principles') that have emerged from four regional and one global workshops organised for Transform Health, by PATH along with AeHIN, RECAINSA, BID Learning Network and Mwan Events.

This consultation was complemented by a Wilton Park youth-focused consultation with young experts from around the world, who gave their feedback on the proposed health data governance principles. This report is a summary of that consultation and findings will feed into a finalised set of proposed health data governance principles which will be published for public comment at the time of the Commission's report launch.

"These principles are needed in these times of uncertainty and shifting mindsets. We are going towards universality, which is rooted in local ownership. This is good for the nexus of youth, technology and movement building."

Overview of data governance principles

1. The Commission will soon release its final report on the 25 October at the World Health Summit. The final Commission report is separate from the health data governance principles that are under discussion today but they are supported by the Commission's work.
2. The Commission's report found that the health sector does not always take into account other sectors and that the health sector is sometimes naive in how such data is being used. In reality, health data is frequently an entry point for longer points of data extraction.

“The youth are the users of future global health and if we are not engaging and supporting donors to work with young people we are missing a central perspective”

“When countries engage young people they can make big strides, but it is not common and there is a gap.”

“Young people are not homogenous. They are complex and the principles will translate very differently across different subsets of young people. Let’s continue to have more diverse youth representation to analyse the principles and make them robust and equitable for all.”

3. The health data governance Principles are not from the Commission report; they are a CSO-driven effort developed by country leaders convened by Transform Health regional partners. Among other things, Transform Health was created to take forward the recommendations of the Commission and the Commission supports the development of the Principles. These Principles are working towards new vision of data solidarity, developed by leaders for leaders.
4. The goal of these Principles is to provide a globally unified approach to the Governance of health data and to help guide the discussion as we move towards data solidarity which is a defining feature of the Commission report and of these Principles
5. The process for building the Principles are flexible and still on-going. This youth consultation sought feedback on how the Principles resonate with young people and to what extent is it possible to overcome the tensions that exist within the Principles.
6. The principles cut across health data and data for health and other terms to support health decisions. This also means reimagining and challenging the structures that can silence vulnerable communities. The Principles aim to guide behaviour sanctions and policies for country leaders, policy makers and diverse stakeholders and to remain the core tenets of health data governance that allows a flexible environment to allow everyone to benefit from health data. It is important for health data governance to be forward looking and see rising issues especially in emergency technologies where inclusion is not properly fulfilled.
7. Supporting innovation and youth movement building is critical. Although several landscapes have been mapped globally and locally, there still lacks a clear landscape about what it means to involve young people in health, technology, governance and decision making.
8. It is important be sure the Principles go to the very core of what it means to build infrastructures of pubic health and attach a public value to health data.
9. The Principles differ from two previous sets of digital health principles which focused on and were developed mainly by development partners and donors, namely: The Principles of Donor Alignment for Digital Health and Global Digital Development Principles. These new Health Data Governance Principles come from countries themselves, rather than the global community, and are focused on actual use of technologies and the data they provide to grow health equity. They will ultimately support countries to hold donors accountable. In relation to other global frameworks, the Principles will inform the global governance framework on health data, which is currently being conceptualised at WHO.

Group feedback on the Principles

Youth participants broke up into small groups to discuss key questions in regards to the seven main principles.

- What is lacking in the Principles for young people? Do the current Principles reflect young people's needs, priorities, and expectations?
- How can young people (and women, people of diverse races, sexualities) be supported to take ownership of the Principles and hold stakeholders more accountable to the Principles?
- What governance and policy reforms would young people like to see as a result of the Principles?

Annex 1 contains the full set of responses from each group, and below is a short summary of some of the key feedback for each question.

“It is important to build a principles on cyber security - every principle falls apart without security.”

“This youth consultation is late as the principles are already developed - bring young people in early. If things are flexible and iterative and less fixed young people will be able to contribute more easily.”

Question 1: What is lacking in the Principles for young people? Do the current Principles reflect young people’s needs, priorities and expectations?

Participants felt that the Principles must:

- Be more inclusive including citizens, residents, refugees and specifically address disabled people. Do not tokenise inclusion.
- Protect minors and adolescents.
- Embed universal health coverage and people-centredness.
- Look for intersections between the individual and society, including with geo-political power structures.
- Define data for health more clearly: what does it mean, and what should it include? Be accurate with health literacy, and use national and regional examples to reduce jargon.
- Include an explicit focus on the protection of data, which is fundamental. Follow up questions /concerns included: how are you protecting data?; and if different standards exist, it is more difficult to be interoperable especially with a range of software implementers.
- Cybersecurity should have its own Principle as all the principles fall apart without security.
- There is no reference to globally established principles on balancing individual protection and data in the public interest.
- There is a need to be iterative and continue consulting with development of definitions. The definition of youth needs to be included in the Principles and take into account the uniqueness and importance of this non-homogenous group.
- Consent is a must and not optional: be clear where data will be used and why data is necessary. Support 'informed consent': are definitions and indicators of informed consent clear and understood?

Question 2: How can young people (and women, people of diverse races, sexualities) be supported to take ownership of the Principles and hold stakeholders more accountable to the Principles?

Responses included:

- Be specific on what is needed from young people with a systematic approach, and clear guidance on spaces, meaningful contributions, and support available.
- Education and capacity building, including training and mentorship are needed so young people can participate, especially to improve digital health literacy.
- Young people need to be supported with skills and capacities to hold leaders to account in their countries.
- Use the Principles to give access to decision making to vulnerable groups, especially concerning their own data.
- Create new and use existing programmes and forums where youth are engaged with leaders on these Principles, and support intergenerational dialogue and leadership.
- Make the Principles relatable to young people and support health literacy. Young people should be able to see themselves reflected in the principles - there could be a youth friendly version of the principles.
- Build knowledge and understanding about protection among young people and children, especially that personal data is lifetime data.

“Interoperability is not only about sharing data it is about shared values of equity and human rights.”

“We need enhanced digital literacy for youth to understand these principles. There are few young people in this space who can engage with the content of the principles.”

- How are we defining young people? 'Young people' is a broad concept - for these principles to have bite we need to understand how young people experience health data and data for health.
- Educate health providers, patients, and the public on data governance. What's the benefit of data? How does the public understand this?
- Wording and communication that enables young people to take ownership and have a voice is needed.

Question 3: What governance and policy reforms would young people like to see as a result of the Principles?

- Embed digital health and literacy skills more deeply in the education system and curriculum, in health and other sectors such as health economics, research, and ethics.
- Systems and interoperability are crucial to ensure a supportive environment.
- When data is not solely traditional health data, the Principles need to remain relevant.
- This agenda should not just stay in the health space, but move to UN level. Data governance is important in many other domains – such as trade and commerce - to improve governance and accountability for data in general.
- Framework legislation for national data governance is needed which is replicable and adaptable to different regions.
- Independent autonomous agencies that will follow up with implementation at national level should be created.
- The recognition of digital rights as a form of human rights, should be incorporated into existing country, regional and global frameworks.
- Youth needs to be engaged in policy development from start and with more substantive capacity.
- Provide funding for youth led organisations to do work.
- Data governance means different things to different stakeholders. Fund regional research to explore what this looks like in practice.

Resources

[Youth engagement in digital health: a critical perspective towards meaningful youth agency in governance](#)

Conclusion

This consultation was an opportunity for young people to contribute clear direction and ways forward for the Principles, so they are better positioned to provide a unified approach to the governance of health data. This was not a 'one off event' and the process is designed to be iterative with future opportunities for engagement.

Alison Dunn

Wilton Park | August 2021

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Annex 1

Miro Board responses in small groups

Group 1. Focus area: key definitions, prioritise equity

What is lacking in the Principles for young people? Do the current Principles reflect young people's needs, priorities and expectations?

- Ensuring data and technology deliver value.
- Role of community data versus individual data; this links to data privacy.
- Be inclusive. Citizens, residents, refugees.
- Be clear on what is health data versus data for health (ex: demographic data).
- Individual versus society: look for intersections, not bifurcations.
- Don't tokenise inclusion. Speak more of agency.
- Introduce other principles. How do they relate?
- Can we use these principles to guide national ownership and accountability?
- Define data for health more clearly. Why this is important and what it should include? Think of biases.
- What does data privacy practically mean? Intersectionality - take perspectives from doctors, students, other professionals. What does it mean to them?
- Use Principles to intersect with power structures. How do we do this beyond buzzwords?
- Learn from Digital Development Principles. These Principles will develop like those. They can be living and incorporate perspectives.
- Principles to mature with further evidence. Geopolitics will influence intersections with power structures.
- Answer questions on individuality and ownership. Establish trust structures. Take perspectives from around the world. Balance ability to influence.

How can young people (and women, people of diverse races, sexualities) be supported to take ownership of the Principles and hold stakeholders more accountable to the Principles? What governance and policy reforms would young people like to see as a result of the Principles?

- More definitions necessary. Be accurate with health literacy: take national/regional examples to reduce jargon.
- Address people with disabilities. Make these Principles more inclusive.
- Equity involves empowering communities to have access to their data + act based on it.
- Use Principles to give access to decision making to vulnerable groups: especially their own data.
- Focus on non-digital aspects of health data: with CHWs, on the ground workers, implementers.
- Recognise privilege. Go beyond high level.

- We need significant institutional changes to ensure greater inclusion and ownership.
- Restructure funding sources to consider youth in policies, programmes.
- Educate health providers, patients, public on data governance. Simplify. What's the benefit of data? How does the public understand this? Reduce misinformation.
- Data governance means different things to different stakeholders. Fund regional research as well.
- Educate and learn from engineers + IT as well. How can we ensure cross learning?
- Cohesive collaboration with intersectional sectors. Mixing health + migration data can cause discrimination.
- Consultations are often one off and extractive. How do we cross learn?

Group 2 - Focus area: Build trust, Establish data ownership and rights

What is lacking in the Principles for young people? Do the current Principles reflect young people's needs, priorities, and expectations?

- Data Protection --> Implementation of digital tools that rely on
- health data - these principles don't have explicit focus on protection of data is fundamental. How are you protecting the data? If different standards exist, it is more difficult to be interoperable.
- Protection of minors.
- Piracy - who will have access to the data?
- Principle: protecting minors and adolescents.
- How to link principles to UHC?
- Accountability embedded in the principles, but can this be a principle in itself.
- Patient centeredness as a principle.
- Person has a right to withdraw at any time. Sign up in the beginning, but if later on you withdraw it.
- Context specific solutions. How can the system respond to specific needs if they are missing out on services.

How can young people be supported to take ownership of the Principles and hold stakeholders more accountable to the Principles?

- Programmes where youth are engaging with leaders on these principles. Deliberately create forums and review this periodically. Embed these in the way forward for these principles.
- Types of different fora for stakeholders to engage, youth to engage even in existing fora.
- How do we get young people involved in this if they don't even think about this. How we engage young people is important when this impacts them but they may not be thinking about it. Making it relatable to young people and building civic literacy.

- Intergenerational dialogue, leadership. Empower the young health professionals to know and understand these principles. Since the beginning of their training so they can explain it clearly to their patients.

What governance and policy reforms would young people like to see as a result of the Principles?

- At the student level can embed digital health more in the education/curriculum. Not just health professionals but other sectors, health economists, health researchers, ethical committees, etc.
- Build literacy skills into existing structures.
- Pathway/framework for implementation.
- Evaluating and monitoring.
- Relevance of principles when data is not solely health data. Records but also data from apps... do these principles go beyond the traditional health data.
- Health system policies where we demand updated data.
- Different acts that have been passed that have shown that such systems can create a more supportive environment. Holistic and robust.
- Push for Interoperability in general at a policy level - we shouldn't be going to numerous departments to access certain data/information nor to access ours.

Group 3 - Focus area: Protect the individual, Enhance health systems and services

What is lacking in the Principles for young people? Do the current Principles reflect young people's needs, priorities, and expectations?

- Cybersecurity is mentioned several times but it does not have its own principle and it should do; all the principles fall apart without cybersecurity.
- Personal data is lifetime data; do young people and children understand that they should be protected? Knowledge building and education for future protection is important. (Digital literacy)
- How are we defining young people? 'Young people' is a broad concept - for these principles to have bite we need to understand how young people experience health data and data for health.
- Youth - as a diverse group - is not mentioned in the principles at all - hard for youth to identify with and feel supported. Terminology in principle is very generic - can we specifically refer to young people? Who is the data subject and how is a young person represented?
- Defining inappropriate use of health data but we need to define the penalties when this is done.
- Language weak? 'Should' is not strong enough.
- No reference to globally established principles on balancing individual protection and data in the public interest.
- Protecting children's data is another area - how do we build protective structures for this category which is different to general protections?
- No reference to youth, civil society and grassroots and how governments should approach these organisations. Utilisation of the principles is important - there is an intergenerational gap the principles do not touch on.

How can young people be supported to take ownership of the Principles and hold stakeholders more accountable to the Principles?

- Be specific on what you want from young people. Often participation is tokenistic. Clear guidance on spaces, meaningful contributions, support available etc is needed for a systematic approach. No mention of this anywhere.
- For all of core tenets, there could be specific notions of what young people and children can provide as valuable inputs and how they can do this.
- This youth consultation is late as the principles are already developed - bring young people in early. If things are flexible and iterative and less fixed young people will be able to contribute more easily.
- It is also about mandating audits where young people can demand accountability, and question how systems are launched and work.
- Education and capacity building are needed so young people can participate - training and mentorship.

What governance and policy reforms would young people like to see as a result of the Principles?

- Young people need to be supported with skills and capacities to hold leaders to account in their countries.
- This should not just stay in the health space, but move to UN level. Data governance is important in many other domains - e.g. trade, commerce etc - to improve governance and accountability for data in general.
- Framework legislation for national data governance is needed which is replicable and adaptable to different regions.
- Policy ask for creation of independent autonomous agencies that will follow up with implementation at national level.
- Strict and simple to understand transparency principles which can be implemented - actionable frameworks for companies and institutions.
- Recognition of digital rights as a form of human rights, incorporated into existing country, regional and global frameworks.

Group 4 - Focus area: Promote data sharing and interoperability, Facilitate innovation

What is lacking in the Principles for young people?

- Difference between young people and older generation is platforms which might be used.
- Interoperability with other software and tech- how do we ensure other software implements same principles.
- How do we ensure policies are standard across sectors and implemented?

How can young people be supported to take ownership of the Principles and hold stakeholders more accountable to the Principles?

- Support 'informed consent': is definition and indicators of informed consent clear and understood?
- Does data provider understand end use of data?
- Consent is a must and not optional: be clear where data will be used and why data necessary.

- Need to ensure young people are appropriately informed and understand about collection, share and use of their data.
- Challenge is implementation: can we provide young people more agency-language which is more equitable in their engagement, decision making & partnership.
- Need to be able to be iterative with development of definitions.
- Mapping at Berkman Klein: do young people have same understanding as adults re data collection and use? Evidence showing they are not.

What governance and policy reforms would young people like to see as a result of the Principles?

- Promote disaggregation of data for data analysis.
- Engage as members of Global Governance Council.
- Highlight engaging young people in principles so people can see themselves in the principles-also for vulnerable groups.
- Need wording which enables young people to take ownership and have a voice.
- Need youth engaged in policy development from start and in more substantive capacity.
- Provide funding for youth led organisations to do work.