YOUTH: KEY DRIVERS OF DIGITAL ADOPTION AND HEALTH DATA GOVERNANCE

By: Brian Li Han Wong, Louise Holly, Whitney Gray and Robin van Kessel

Summary: Digital transformations in health are inherently data driven. For young people, the sharing of personal health data and other data for health presents both opportunities for improving personal and public health but also poses risks to privacy and the protection of other rights. Weak governance of digital health and data – coupled with inadequate investment in digital, health and civic skills and literacy – increases young people's vulnerability to online harms and mismanagement of their data. As prominent drivers of digital adoption and digital governance, youth must be at the centre of reforming digital and data governance so that better health futures can be realised.

Keywords: *Data Security, Digital Health, Digital Literacy, Governance, Health Data, Youth*

> **#EHFG2021 – EVENING SESSION 2:** Hey Mary, by the way, thank you for your data: Better data, bolder economy, brighter future

Brian Li Han Wong is Youth Officer, **Louise Holly** is Policy and Research Consultant, **Whitney Gray** is Youth Coordinator and Policy and Research Officer, Secretariat, The Lancet and Financial Times Commission on Governing Health Futures 2030: Growing up in a digital world, Global Health Centre, The Graduate Institute, Geneva, Switzerland; **Robin van Kessel** is Assistant Professor of International Health at Maastricht University, Maastricht, Netherlands. Email: brian.wong@graduateinstitute.ch

Introduction

"There are currently 375,000 health and fitness apps on app stores, which gather approximately five million downloads per day."

– Liz Ashall-Payne, Chief Executive of ORCHA during The King's Fund event on 'Digital innovations in health and care: Looking ahead'.

Digital transformations in the context of health and wellbeing align with broader existing definitions of digital health, such as the one proposed by Paul Sonnier: "the convergence of the digital and genomic revolutions with health, health care, living, and society".[1] This framing of digital health brings together the health and digital fields, which are both inherently data driven. With respect to the data that are both directly and indirectly relevant for health and wellbeing, two types are important: 'health data' and 'data for health' (**see Box 1**).

With the increased adoption of digital health tools and services – and the potential for health data to be sought for commercial and other non-health purposes – the need for good data governance is rapidly growing (**see Box 1**). While the importance of involving youth* in data governance has been emphasised manifold,[2–4] it is yet to be operationalised at scale. This article argues that youth – as prominent drivers of digital innovations and adoption – must be at the centre of digital and data governance, given they

* Youth refers to people aged 15–24 as per United Nations terminology.

Box 1: Distinguishing between health data and data for health

'Health data' refers to information that directly relates to an individual's health and wellbeing or to the health services an individual receives. This can be collected by health care providers, patients, or by private providers of technologies and digital platforms.

'Data for health' refers to data that is not directly associated with an individual's health and wellbeing but may be used to support health-related decisions (e.g., real-world data: demographic data, telecommunications data, and weather data). This might include personal data that is not directly health-related (such as location data, customer shopping data or social data collected through smartphones or self-tracking devices) but might be used by health care providers, insurers, or decision-makers.

stand to inherit the potential (positive and negative) changes brought about by digital transformations.

Safeguarding health futures by governing digital transformations in health

Digital transformations comprise the social, technical, political, and financial processes of integrating digital technologies and data into all areas of life as well as the resulting changes that they bring about. Increasingly recognised as determinants of health, digital transformations can have direct and indirect impacts on driving (in)equity in health and wellbeing.[5] Moreover, they interact with many other social, political, commercial, and environmental determinants which shape health futures.[5] As such, the various digital determinants of health encourage health governance to address both the direct influences of digital technologies and data on health, as well as the indirect ways in which broader digital transformations influence health equity. A solidarity-led approach to data governance is important to build a culture of data justice and equity and to balance the collection, use, and sharing of health-relevant data for public good with protecting people's most personal and sensitive data.[5] Only through a precautionary but value-driven approach to data governance, will governments be able to realise the full potential of digital transformations for all people, including youth.

Individual rights to privacy and data protection are captured in various instruments including the European Convention on Human Rights, the 2016 General Data Protection Regulation (GDPR), and the Council of Europe's Convention No. 108+ for the protection of individuals with respect to the processing of personal data. However, recent events such as the Health Services Executive (Irish state health care system) ransomware attack and the Medicaid data breach have reemphasised the need for further action to safely and securely store health data. Such data breaches are not only an infringement of privacy, as sensitive data about individuals become available without their consent, but these data breaches can also have long-term health effects by undermining public confidence in sharing health data and use of digital health tools. As such, data security can be considered a key digital determinant of health that should be safeguarded for the protection of health futures.[5]

> "youth must be at the centre of digital and data governance

Despite the risks that data may not be held securely, it can be in the interest of the young person to share their personal data with certain actors, including private entities. For example, there are benefits to a patient sharing their medical history with their health professional or using a digital health app to monitor personal vital statistics. However, strong regulation of data sharing processes is essential to safeguard data for all parties involved and prevent data from being misused. Digital trust and a commitment to protecting digital rights become central elements in building an ethical digital infrastructure.[5]

We have touched upon the potential benefits and risks of sharing personal health data. While it can pose a risk to individual privacy, in the spirit of solidarity it may be beneficial to share health data for the public interest and to fully realise the right to health. For example, contact tracing amidst the COVID-19 pandemic demonstrated how sharing personal health data can be a beneficial measure for public health responses despite risks to personal data security and privacy.[6] In the face of this dichotomy, it is increasingly important that young people have the awareness, capacity, and competency to identify when it is appropriate to share their health data and how to do so safely.

Youth as key drivers of digital adoption

In his book *Diffusion of Innovations,* Rogers outlined a bell curve that depicts five categories of adopters: innovators, early adopters, early majority, late majority, and laggards.[7] When applying this theory to the adoption of digital innovations, youth is characterised as either an innovator or an early adopter.[5,8,9] Put simply, the two categories with the highest level of digital adoption, youth, are among the first 16% of people that adopt a digital innovation and spread it to other population groups.

This level of adoption of digital technologies is not surprising given the prominence of digital connectivity and skills among youth and adolescents. Nearly 69% of global youth are connected to the Internet, compared to just over half (51%) of the overall population.[10] Although youth are more connected, it is not a homogenous population with differences seen within and between countries. Globally, 58% of school-age children from the richest households have internet connection at home, in contrast to

©Floris Oudshoorn of Comic House/EHFG 2021

only 16% from the poorest households. Additionally, the same divide exists between countries based on levels of income. Less than 1 in 20 school-age children from low-income countries are connected to the Internet at home, compared to nearly 9 in 10 from high-income countries.[11]

> digitally vulnerable population groups should be put at the centre

Similar to higher rates of connectivity among youth, they also possess more digital skills compared to other age groups, but such skills are not universal. A recent analysis of Eurostat data highlighted that complex digital skills are considerably more common among youth and adolescents in Europe (22–85%) than older age groups in the same region (55–64 years: 5–44%; 65–74 years: 1–23%).[12] Although we need to be mindful of two common biases in digital skills: education- and sex-based biases; the fact remains that youth as a population group develop complex digital skills more commonly even when accounting for these biases.[12,13]

Despite the prevalence of complex digital skills among youth there is still a wide range (22% to 85%) of how common these skills are within the youth population in Europe.[12] There is still a substantial proportion of youth that experience difficulties in navigating the digital world – particularly in managing and protecting their personal data. Lack of transparency about how personal data is collected, stored, and used indicates that most young people (and adults) are unaware of the data trails they leave in online environments or who has access to their data. Digital and social determinants of health likely affect the development of complex digital skills,[5,9] particularly in youth from disadvantaged and vulnerable communities (e.g. gender and sexual minorities, people living with disabilities, ethnic groups, and other underrepresented groups) who can experience further difficulties in developing complex digital skills.[5,9]

The catalytic role of youth in digital adoption not only applies between age groups but also within youth. When considering the adoption curve of digital innovations, the digital skills levels of different age groups in Europe lead to two key actions. Firstly, digitally vulnerable population groups should be put at the centre of the development process of digital innovations (for more details on how this may look, see [14]). In doing so, accessibility of digital innovations can be better ensured for these groups. Secondly, youth should be recognised and well-positioned as catalysts for the proliferation of digital innovations alongside their increased likelihood of having more diverse digital skills. Given their inherent affinity for adopting digital innovations alongside their increased likelihood of having more diverse digital skills, they are in the prime position to assist more digitally vulnerable populations in adopting such transformations.

Involving youth in digital health and data governance

The underdeveloped digital regulatory ecosystem continues to make young people vulnerable to various challenges and potential harms on digital platforms. Although youth have on average higher levels of engagement with digital platforms and technologies, few are equipped with digital skills around data protection and privacy to help them safely navigate digital ecosystems. Digital, health, and civic literacy are vital components to build this capacity in youth so they can make the most effective use of digital technologies, manage their data, and determine the reliability of online health information.[5]

Young people's right to participate in decision-making that affects their lives is enshrined in the UN Convention on the Rights of the Child and other international and European guidance on civic participation. Research and consultations with youth carried out by the *Lancet* and Financial Times Commission on Governing Health Futures 2030 (GHFutures2030) indicate that youth are eager to play a greater role in digital and data governance, but lack opportunities for participation, which – coupled with inadequate skills and literacy – present barriers for youth to meaningfully engage in such governance processes.[3]

Youth not only recognise the great potential for digital transformations to support them in learning and gaining new skills but have also highlighted the positive implications they can have for policy, practice, and research internationally.[15] With improved digital skills and autonomy,

youth can obtain further knowledge about digital health, the data generated, how it is used, and their rights over it. The recently launched GHFutures2030 Youth Statement and Call for Action presents a wake-up call for stakeholders to ensure that efforts to meaningfully involve youth in digital and data governance mechanisms must be grounded in a human rights-based approach.[15]

Looking ahead

"Data is the new gold; it is enabling decisions on marketing, politics, and many other areas"

– His Excellency Mr. Munir Akram, President of the Economic and Social Council during the UN High-level Thematic Debate on Digital Cooperation and Connectivity

Data is driving digital transformations in all sectors, health in particular. For these transformations to have a positive impact on the health and wellbeing of children and young people, they need to be shaped by and co-created with those who stand to inherit the changes brought about. Governments must act to safeguard health futures by pushing for data governance mechanisms which balance the public value of data and individual rights, monitors stakeholders' compliance with existing laws and regulations, and closes the digital connectivity and skills gap to ensure youth are enfranchised and have agency to meaningfully participate in governance processes which concern their personal data. Youth in Europe can lead a solidarity-based approach to the digital transformations in health as champions for data security and governance in a global setting to shape and realise equitable and sustainable health futures for generations to come.

References

1 Sonnier P. *The fourth wave: digital health.* Independently published, 2017.

2 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 Bull #157 2021.* Available at: https://www.medicusmundi.ch/en/advocacy/publications/mms-bulletin/digital-health-a-new-era-of-global-health/kapitel-3/youth-engagement-in-digital-health-a-critical

3 Governing Health Futures 2030 Commission. *Digital health futures: Insights into young people's use and opinions of digital health technologies.* Summary report of a 2020 U-Report poll. Geneva, 2021. Available at: http://www.governinghealthfutures2030.org/wp-content/uploads/2021/09/Digital-health-futures-U-Report.pdf

4 Dzikunu R, Gray W. Young people call for more decentralised youth consultations on health data governance principles. *Gov Health Futur 2030.* 2021. Available at: https://tinyurl.com/42pymvyy

5 Kickbusch I, Piselli D, Agrawal A, et al. *The Lancet* and Financial Times Commission on governing health futures 2030: growing up in a digital world. The Lancet 2021;1–50.

6 Rogers EM. *Attributes of Innovations and their Rate of Adoption.* Diffus Innov 4th ed New York, NY: The Free Press, 1995:204–51.

7 Gunasekeran DV, Tseng RMWW, Tham YC. et al. Applications of digital health for public health responses to COVID-19: a systematic scoping review of artificial intelligence, telehealth and related technologies. npj Digit. Med. 2021;4:40.

8 Wong BLH, Gray W, Holly L. The future of health governance needs youth voices at the forefront. *The Lancet* 2021 Oct;1–2.

9 Scheerder A, van Deursen A, van Dijk J. Determinants of Internet skills, uses and outcomes. A systematic review of the second- and third-level digital divide. *Telemat Inform* 2017;34(8):1607–24.

10 International Telecommunication Union. *Measuring Digital Development: Facts and Figures 2020.* Geneva, Switzerland: International Telecommunications Union, 2020. Available at: https://www.itu.int/en/ITU-D/Statistics/Pages/ff2020interactive.aspx

11 United Nations Children's Fund, International Telecommunication Union. *How many children and young people have internet access at home? Estimating digital connectivity during the COVID-19 pandemic.* New York: UNICEF, 2020.

12 van Kessel R, Wong BLH, Rubinić I, Czabanowska K. Is Europe prepared to go digital? Making the case for developing digital capacity: an exploratory analysis of Eurostat survey data. *PLOS Digital Health* 2022. Available at: https://journals.plos.org/digitalhealth/article?id=10.1371/journal.pdig.0000013

13 Honeyman M, Maguire D, Evans H, Davies A. *Digital technology and health inequalities: a scoping review. Cardiff:* Public Health Wales NHS Trust, 2020: 44. Available at: https://phw.nhs.wales/publications/publications1/digital-technology-and-health-inequalities-a-scoping-review/

14 United Kingdom Information Commissioner's Office. *Introduction to the Age appropriate design code. ICO,* 2021. Available at: https://ico.org.uk/for-organisations/guide-to-data-protection/ico-codes-of-practice/age-appropriate-design-code/

15 Wong BLH, Gray W, Stevens EAG, et al. GHFutures2030 Youth Statement + Call for Action. *Gov Health Futur 2030;* 2021. Available at: https://els-jbs-prod-cdn.jbs.elsevierhealth.com/pb-assets/Lancet/stories/commissions/governing-health-futures-2030/GHFutures2030_Youth_Statement-1634917151153.pdf