



REFLECTION PAPER

DATA-DRIVEN HEALTHCARE AND THE DIGITALISATION OF SOCIETY – THE STAKES FOR PUBLIC HEALTH | EXECUTIVE SUMMARY

Introduction

This brief contains reflections and recommendations about what stakes are for public health in an increased data-driven healthcare and digitalisation of society. These stakes go well beyond the health sector and invite the public health community to start collaborating with organisations in digital rights, gender equality, and environmental and economic justice as well.

The outbreak of the COVID-19 virus and digital applications to combat spreading of the virus has speeded up the discussion about 'digital health', data protection, and potential infringements of human rights. The discussion focussed especially on public health surveillance using big data to track disease patterns and the use of digital proximity tracking technologies for COVID-19 contact tracing. It triggered a range of academic publications highlighting ethical considerations regarding the technical applications (apps).¹⁻³

Digital health should be an integral part of health priorities and benefit people in a way that is ethical, safe, secure, reliable, equitable and sustainable.⁴ This cannot be taken for granted. Health data is part of the network economy that is based on the 'winner-take-all' principle.⁵ Also, concerns are raised about how disease stereotypes (e.g., heart attack, depression, asthma) are translated to technology and may lack gender and ethnical diversity perspectives.⁶ Digital public health technologies carry an inherent risk of discrimination.³

These developments and concerns indicate that 'digital health' might become even bigger a topic of importance for the public health community – in its design and its implementation. Civil society will need to play its role regarding flagging potential pitfalls, keeping public values front and centre, and help identifying what 'empowerment' means for 'whom'.

What are data-driven solutions in public health?

In the age of Big Data, the life science and the healthcare are flood from information and data sets.⁷ Data are used to evaluate public health decisions, policy and resource allocation. (Big) data are also used for digital health technologies.

Digital health technologies encompass a wide range of devices and software.⁸ These include the use of social media by both members of the lay public and healthcare or public health professionals to discuss health and medical issues and disseminate information; remote healthcare consultations and patient self-care using digital technologies (telemedicine and telehealth); the use of virtual reality in medical training; the rapidly expanding number of mobile applications ("apps") devoted to health and medical matters [...]; health informatics systems in healthcare delivery; public health surveillance using big data to track disease patterns; wearable self-tracking devices and gaming technologies for monitoring bodily functions and activities using sensors; health promotion employing social media and text messages; 3D printing of medical devices and prosthetics; and

community development and activist initiatives involving citizen science/citizen sensor activities to generate environmental information on their local area.¹

Public health surveillance also involves the use of digital proximity tracking technologies for COVID-19 contact tracing.^{3,9}

Benefits and shortcomings of data-driven healthcare development

Big Data offers paths and solutions to improve health of individual persons as well as to improve the performance and outcomes of healthcare systems.¹⁰ The digitisation of health data, for instance, creates opportunities for more personalised healthcare and prevention.¹¹ Digital health technologies based on data and Artificial Intelligence can reduce costs in healthcare, improve patient safety, empower patients and improve the quality of diagnosis, therapy, patient journeys, billing and logistics.¹²

However, digital health initiatives can amplify socioeconomic inequalities and contribute to healthcare disparities. Even within high-income countries, susceptible groups, such as those in low-income neighbourhoods or remote regions, might not have access to broadband signals, smartphones, or wearable technology such as smartwatches.¹⁰ This could threaten the right to health.

Digitalisation has been compromising certain public values such as privacy, digital security, equal treatment and freedom of expression.¹⁻³ Also, the governance system – the collection of actors and institutions responsible for defining social and ethical issues and placing them on the agenda – has been insufficiently prepared to protect these public values.¹³ It is not always apparent where vested interests lie in the provision of medical information in apps either for lay people or members of the medical.^{14, 15}

IT giants such as Amazon, Google, Facebook and Alibaba, for example, have access to huge volumes of personal data and use this for their own commercial aims.¹⁶ ‘Nearly every product or service that begins with the word “smart” or “personalised”, every internet-enabled device, every “digital assistant”, is simply a supply-chain interface for the unobstructed flow of behavioural data on its way to predicting our futures in a surveillance economy.’¹⁷ At the same time, there is a lack of awareness about how the General Data Protection Regulation could be used to prevent undermining data privacy and security.¹⁸

General Data Protection Regulation

The European Union has a data protection legal framework. Developments at the national level of EU Member States all need to follow data protection rules and principles as provided by EU law. In the case of the COVID-19 pandemic it regarded for instance mobility data for heat maps and modelling, health data for research purposes or proximity data for contact tracing. Data protection includes ensuring protection of fundamental rights and freedoms.¹⁸

The European Data Protection Board (EDPB) represents the agreed position of all national Data Protection Authorities (DPAs). DPAs are the only administrative entities that have competence to enforce the GDPR and the Law Enforcement Directive at national level of EU Member States, both against government bodies and private organisations.

There are not enough safeguards in the data chain, i.e., the processes of generating, accessing, sharing and using health data.¹⁹ And there are limits to personal health management; equal access to healthcare and health are not sufficiently guaranteed.¹³

Digitalisation: lessons learned for the health sector

Sectors outside the health sector, such as finance and banking, transport, industrial production and retail 'have all experienced it: you go digital or you disappear.'¹²

A study that was drawn up for the European Economic and Social Committee explored the impact of digitalisation on employment, enterprises and labour relations in terms of the creation, transformation and destruction of jobs, employees' and employers' altered roles, and changes in the organisation of work.²⁰ It showed that in traditional businesses and industries digitalisation affects existing organisational and management structures, which is most visible due to the higher flexibility and fragmentation of work, changing work monitoring methods, recruitment strategies, and skill and training needs. More generally, the real challenge for industrial operators is whether they, as established firms, can engage their own digital transformation before disruptive competition forces them out of business.

According to the researchers, key factors for successfully adapting enterprises to the changes brought about by digitalisation are the ability to collect and exploit data, the interconnection of value chains, the creation of digital customer interfaces, and the mitigation of cyber threats.²⁰ These are potential lessons that can be drawn for the healthcare sector.

However, these traditional businesses do not need to uphold public health values and are based on competition rather than on cooperation.¹²

For the health sector, additional questions should be asked such as 'can we trust big tech and their acolytes and subsidiaries with our health data? Can we ever be sure that their services will not be solicited by foreign failing states, guarantee that they and our data will not merge with companies and databases in the hands of oligarchs who do not feel constrained by the rule of law or principles of ethics?'¹²

In addition, as part of the COVID-19 pandemic surveillance tasks, such as source and contact research had been outsourced to call centres. Many more people had access to identity-relevant data in the health domain. Data can leak due to technological failures or human failures, by accident or on purpose.²¹

It is against this background we need to situate the discussion about how to move forward data-driven healthcare and the digitalisation of society?

Moving forward

Digitalisation in health care may affect certain goals or certain groups positively, while at the same time negatively affecting others.²² The debate on the deployment and influence of digital technologies has long focussed on technology and was based on the assumption that it will automatically lead to social progress and was considered 'value-free'. However, this is not the case and the public health community should put a focus on the interaction between digitalisation and values.¹¹

Values in design

It is important that digital health solutions are based upon cooperation between users, healthcare practitioners and researchers.¹¹ This way, it ensures the quality of the data and that people are being protected against the unwanted use of their data. This cooperation supports healthcare that respects human dignity. TU Delft uses the wording of 'value sensitive design': all stakeholders should be involved in the design of a digital health technology and it should be based on values such as privacy by design linked with health system goals.¹²

Values in implementation

Accessing personal health data for unethical purposes is always a threat. This may happen on purpose or by accident. This implies that from the beginning of developing a particular technology privacy protection measures need to be put in place. It also implies that people working with health data (from AI-experts to call centre workers) need to comply with legal obligations to secure the data against unauthorised access (and must be informed about this).

From 'winner-takes-all' to 'regenerative'

The whole data chain of digital health technologies is part of the economic system. Tasks that are outsourced to call centres run the risk that they are performed by employees whose working conditions are compromised and whose tasks are not fairly remunerated.²³ Also, how can the environmental footprint of digitalisation be decreased?²⁴ Throughout the digital health data chain profits should not be made at the expense of exhausting the system. The economic system must become 'regenerative' instead of 'extractive'.^{25,26}

Data protection

Guidelines of the European Data Protection Board (EDPB) are very important because they represent the agreed position of all national Data Protection Authorities (DPAs). DPAs are the only administrative entities that have competence to enforce the General Data Protection Regulation and the Law Enforcement Directive at national level, both against government bodies and private organizations.

Equally important is the data strategy of DG Connect: it supports establishing nine common European data spaces, including a Common European health data space. Europe has exclusive competence over data, not over health. But one can impact on health (policies) by regulating data: how it is collected, and how it is used.

Ethical considerations

In order to avoid so-called solutionist or instrumentalist approaches (where the focus is on the benefit that the technology itself brings to public health management) to digital public health technologies, the focus should be on public health outcomes, as well as ethical principles guiding these outcomes.² These ethical considerations include ensuring public benefit; ensuring scientific validity and accuracy; protecting privacy; preserving autonomy; avoiding discrimination; be aware of repurposing; setting an expiration; and preventing digital inequality.

Gender and intersectional perspective

To unlock the full potential of new tools, technologies and digital solutions for a healthy society, access to and use of digital solutions might differ by gender.²⁷ The way forward should guarantee equal access for all and therefore include a gender and intersectional perspective. It should also guarantee safety for all users, regardless of their gender and/or ethnicity. Hence, users should be motivated and empowered (in an informational as well as technical sense) to engage in digital health technology. For this, open communication, technical training and education should be offered.²⁸

Initiatives around Digital Health

The data strategy of DG Connect supports establishing nine common European data spaces, including a Common European health data space. This is of interest to the public health community: the European Union has exclusive competence over data, not over health. But one can influence health (policies) by regulating data: how it is collected and how it is used.

The European Parliament resolution of 21 January 2021 on the gender perspective in the COVID-19 crisis and post-crisis period (2020/2121(INI)) provides guidance for closing the digital gap to increase gender equality not only in terms of the labour market but also through access to technologies in the personal sphere.³⁰

The World Health Organization Regional Office for Europe has devoted a 'Flagship Initiative: Empowerment through Digital Health' in its European Programme of Work 2020-2025.⁴

The Lancet & Financial Times Commission 'Growing up in a digital world: Governing health futures 2030' is currently exploring the convergence of digital health, artificial intelligence (AI) and other frontier technologies with universal health coverage (UHC) with fundamental rights and equity being central.³¹

Digital inclusion for all

Developing digital healthcare applications in cooperation with users, healthcare practitioners and researchers can help challenging tech arguments in favour of promoting prevention, health promotion and digital inclusion for all.²⁹ It is therefore important that the diversity of users (sex, gender, age, ethnicity, technical skills etc.) is taken into account.

Recommendations

It is important to realise that (digital health) technology is never neutral, and that there is always an intention in design.²⁵

The public health community should put public values front and centre, such as privacy, digital security, equal treatment and freedom of expression, and decent work.

Putting public values front and centre: guiding questions²⁵

- What values do we prefer? Public values, such as human rights or doughnut economics lead us to governance questions like, how is control organised? How does decision-making take place? Who is participating? Who designs? Who decides? What are the procedures?
- How can we guarantee privacy?
- How can we make digital health technologies accessible for all?
- How can we improve their public character and protect it? How can we facilitate social support for that and political will?
- What could economic models look like that are not based on competition but on cooperation, that optimise public values, are regenerative and respect both human beings and our ecosystem? What natural resources are used and do they contain conflict minerals? What is the ecological footprint of this application? What are the working conditions?

In order to avoid harmful impacts of digitalisation, effective and appropriate governance mechanisms need to be put in place to align digital innovation with public health systems goals.

The public health community should engage with the digital agenda of the European Commission, especially in relation to establishing a Common European health data space.

To guarantee digital inclusion for all and counterbalance the current network economy that is based on the 'winner-takes-all' principle, the public health community should seek collaboration with organisations in digital rights, gender equality, and environmental and economic justice.

References

1. Mello BMM, Wang CJ. Ethics and governance for digital disease surveillance. *Science*. Published online May 11, 2020:eabb9045. doi:10.1126/science.abb9045
2. Gasser U, Ienca M, Scheibner J, Sleight J, Vayena E. Digital tools against COVID-19: taxonomy, ethical challenges, and navigation aid. *The Lancet Digital Health*. 2020;2(8):e425-e434. doi:10.1016/S2589-7500(20)30137-0
3. Sweeney Y. Tracking the debate on COVID-19 surveillance tools. *Nature Machine Intelligence*. 2020;2(6):301-304. doi:10.1038/s42256-020-0194-1
4. World Health Organization Regional Committee for Europe. *European Programme of Work, 2020-2025- "United Action for Better Health in Europe."*; 2020. Accessed October 13, 2020. <https://apps.who.int/iris/bitstream/handle/10665/333908/70wd11e-rev4-EPW-200673.pdf?sequence=1&isAllowed=y>
5. How To Compete In A Winner-Takes-All Digital Global Economy. Accessed February 2, 2021. <https://www.forbes.com/sites/panosmourdoukoutas/2019/02/16/how-to-compete-in-a-winner-takes-all-digital-global-economy/>
6. Oertelt-Prigione S. Prof. Sabine Oertelt-Prigione - Conference Ethics and Digitalization, 01.10.2020, in coop. with VIU - YouTube. Published October 12, 2020. Accessed October 14, 2020. <https://www.youtube.com/watch?v=AEczBDe41o8>
7. Stylianou A, Talias MA. Big data in healthcare: a discussion on the big challenges. *Health and Technology*. 2017;7(1):97-107. doi:10.1007/s12553-016-0152-4
8. Lupton D. Beyond Techno-Utopia: Critical Approaches to Digital Health Technologies. *Societies*. 2014;4(4). doi:10.3390/soc4040706
9. Mooney SJ, Pejaver V. Big Data in Public Health: Terminology, Machine Learning, and Privacy. *Annual Review of Public Health*. 2018;39:95-112. doi:10.1146/annurev-publhealth-040617-014208
10. Whitelaw S, Mamas MA, Topol E, van Spall HGC. Applications of digital technology in COVID-19 pandemic planning and response. *The Lancet Digital Health*. 2020;2(8):e435-e440. doi:10.1016/S2589-7500(20)30142-4
11. Niezen M, Edelenbosch R, van Bodegom L, Verhoef P. *Health at the Centre – Responsible Data Sharing in the Digital Society*; 2019. Accessed October 8, 2020. https://www.rathenau.nl/sites/default/files/2019-06/HealthAtTheCentre_report.pdf
12. Webredactie TU Delft. Saving the life of medical ethics in the age of AI and big data. Published March 26, 2018. Accessed February 14, 2021. <https://www.tudelft.nl/2018/tbm/saving-the-life-of-medical-ethics-in-the-age-of-ai-and-big-data>
13. Kool L, Dujso E, van Est R. *Directed Digitalisation Working towards a Digital Transition Focused on People and Values-The Dutch Approach*; 2018. Accessed October 8, 2020. <https://www.rathenau.nl/sites/default/files/2018-11/Directed%20Digitalisation.pdf>
14. Lupton D. The commodification of patient opinion: the digital patient experience economy in the age of big data. *Sociology of Health & Illness*. 2014;36(6):856-869. doi:10.1111/1467-9566.12109
15. Lupton D. Apps as Artefacts: Towards a Critical Perspective on Mobile Health and Medical Apps. *Societies*. 2014;4(4). doi:10.3390/soc4040606
16. Schobel D. Children are living in both worlds – Healthy Europe Magazine. Published online September 8, 2020. Accessed October 8, 2020. <https://www.healthyeurope.info/children-are-living-in-both-worlds/>
17. Naughton J. "The goal is to automate us": welcome to the age of surveillance capitalism. *The Guardian*. Published January 20, 2019. Accessed October 13, 2020. <https://www.theguardian.com/technology/2019/jan/20/shoshana-zuboff-age-of-surveillance-capitalism-google-facebook>

18. Zanfir-Fortuna G. European Union's Data-Based Policy Against the Pandemic, Explained - Future of Privacy Forum. <https://fpf.org/>. Published April 30, 2020. Accessed February 14, 2021. <https://fpf.org/blog/european-unions-data-based-policy-against-the-pandemic-explained/>
19. Protect digital rights, promote public health: toward a better coronavirus response - Access Now. Accessed February 2, 2021. <https://www.accessnow.org/protect-digital-rights-promote-public-health-towards-a-better-coronavirus-response/>
20. European Economic and Social Committee. *Impact of Digitalisation and the On-Demand Economy on Labour Markets and the Consequences for Employment and Industrial Relations; Final Study.*; 2017. Accessed October 8, 2020. <https://www.eesc.europa.eu/resources/docs/qe-02-17-763-en-n.pdf>
21. Verlaan D. Illegale handel in privégegevens miljoenen Nederlanders uit coronasystemen GGD | RTL Nieuws. Published January 25, 2021. Accessed January 28, 2021. <https://www.rtlnieuws.nl/nieuws/nederland/artikel/5210644/handel-gegevens-nederlanders-ggd-systemen-database-coronit-hpzone>
22. Azzopardi-Muscat N, Sørensen K. Towards an equitable digital public health era: promoting equity through a health literacy perspective. *European Journal of Public Health*. 2019;29(Supplement_3):13-17. doi:10.1093/eurpub/ckz166
23. Berg J, Furrer M, Harmon E, Rani U, Silberman MS. *Digital Labour Platforms and the Future of Work Towards Decent Work in the Online World.*; 2018.
24. Quito A. Find out the environmental impact of your Google searches and internet usage — Quartz. Quartz. Published May 7, 2018. Accessed February 19, 2021. <https://qz.com/1267709/every-google-search-results-in-co2-emissions-this-real-time-dataviz-shows-how-much/>
25. Stikker M. *Het Internet Is Stuk. Maar We Kunnen Het Repareren.* De Geus; 2019.
26. Raworth K. *Doughnut Economics: Seven Ways to Think like a 21st-Century Economist.* Random House; 2017.
27. Oertelt-Prigione S. *The Impact of Sex and Gender in the COVID-19 Pandemic, P9_TA-PROV(2021)0024.*; 2020. doi:10.2777/17055
28. Brall C, Schröder-Bäck P, Maeckelberghe E. Ethical aspects of digital health from a justice point of view. *European journal of public health*. 2019;29(Supplement_3):18-22. doi:10.1093/eurpub/ckz167
29. Hafen E. *Data to the People - A Fair Citizen-Centered Health Data Ecosystem.* The Festival of Genomics & Biodata(2020). Accessed October 13, 2020. <https://frontlinegenomics.com/wp-content/uploads/2020/04/Ernst-Hafen-ETH-Zurich.pdf>
30. European Union: European Parliament. *The Gender Perspective in the COVID-19 Crisis and Post-Crisis Period, 21 January 2021, P9_TA-PROV(2021)0024.*; 2021. Accessed January 29, 2021. https://www.europarl.europa.eu/doceo/document/TA-9-2021-0024_EN.pdf
31. Kickbusch I, Agrawal A, Jack A, Lee N, Horton R. Governing health futures 2030: growing up in a digital world—a joint The Lancet and Financial Times Commission. *The Lancet*. 2019;394(10206):1309. doi:10.1016/S0140-6736(19)32181-6



Co-funded by
the Health Programme
of the European Union