Research study: 'Data-driven healthcare and the digitalisation of society – stakes for public health'
Terms of Reference

About the study

Following the financial and economic crises, the European Union (EU) has made an increased effort to invest in digitalisation, the health sector being no exception. The growth of digital health has been supported at the EU level by, *inter alia*, the eHealth Action Plan 2012-2020[1], the creation of the eHealth Network under article 14 of the Directive on the application of patients' rights in cross-border healthcare[2], and the integration of health into the Digital Single Market.

While an earlier phase of digital health focused principally on establishing the necessary technological infrastructure and the practical tools to enable access to interoperable digital health solutions (involving an array of e/mHealth devices, from hand-held tablets to smartphone apps, wearables, sensor and interconnected objects), the 2018 European Commission (EC) Communication on the digital transformation of health and care[3] signalled a step-change by focusing on data access and sharing as the next and logical phase of digital health implementation in Europe.

The Political Guidelines released by incoming EC President Ursula von der Leyen in the autumn of 2019[4] clearly demonstrate that digitalisation is seen as a vital ingredient for addressing societal challenges including moving towards a climate-neutral economy, improving employment and education, and protecting democracy. In particular, Artificial Intelligence (AI) is viewed by many policymakers as a tool that could help deliver more effective and personalised treatments and interventions, support health systems strengthening and enable better decision-making based on the analysis of large quantities of Big Data.

At the same time, the latest wave of data-driven health solutions poses an ethical dilemma as it challenges and disrupts long-established health systems structures, relationships and ways of working and could mirror rather than reduce existing societal inequalities. For example, not all sources of personal (health) data are equally solid and algorithms may be biased as they do not always reflect the diversity of society at large. While machines are able to process and analyse data a lot faster than humans, the outcomes may be worthless if context-specific information about individuals – such as data about determinants of health and patient history - is not included. The digital health revolution could quickly backfire and threaten our human rights if data protection and privacy regulations are not respected, if personal health data are (mis)used to exclude individuals from accessing health services or insurance and if the potentially weaker performance of the least

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[1] EC COM(2012) 736 final
[2] EU Directive 2011/24/EU
[3] EC COM(2018) 233 final
[4] Von der Leyen, Ursula (2019), My agenda for Europe – A Union that strives for more

health literate population groups results in punishment. Already many powerful tech giants, including Google and Microsoft, are making heavy investments in healthcare, a sector which also offers them valuable personal data that can be used for profiling individuals in return for health data solutions.

The public health community needs to be aware of these trends, which represent a double-edged sword, the promise of better health for all on one side, and the threat of widespread discrimination on the other.

Audience and use of findings

The study will be used chiefly to inform EPHA's future positioning in the area of data-driven healthcare / AI and the digitalisation of society pursued by the European Commission across many policy fields. The objective is to help EPHA and its members to better understand the ethical dimension of this area, e.g. by exploring how developments in health and non-health sectors shaping the determinants of health might influence the attainment of public health objectives in the future.

As the focus is shifting from protecting fundamental public health values such as solidarity, equity and inclusion to individualised solutions based on growing amounts of personal data (including genomic information), the space for advocating population health interventions could be shrinking, especially as technological and economic discourses are closely connected, and technological progress moves a lot faster than the legislative framework. Moreover, non-health sectors are often setting new "norms" that determine the available information and communication technology platforms, data sharing channels, digital devices, etc.

Objectives and questions

The core question of the study is: "How can the public health community best prepare for the entry of data-driven solutions in European health systems and advance its fundamental values?'. Individual sub-questions are open to suggestion and discussion, but EPHA is interested in a number of key areas the study should address:

- How to assess the benefits of and drawbacks of existing and emerging digital technologies on key public health functions, fundamental rights and equity.
- How have other sectors adapted to digitalisation and what are some positive and negative examples? What lessons, good and bad, can be drawn for the healthcare sector? How likely is it that rapid digitalisation in non-health sectors will impact on the level and speed of transformation in healthcare (e.g. new operational practices, relationships, ways of working)?
- In light of recent data scandals, how easy and likely is it that personal health data could be accessed for unethical purposes? How did this occur (describe examples) and what are the potential consequences for individuals, population groups and health systems? To what extent does existing EU and/or national legislation (GDPR, ePrivacy, cybersecurity, etc.) protect individuals from unauthorised data exchanges in an increasingly transnational data ecosystem?
- How should the public health community assess the increased, data-driven commercialisation of healthcare by private companies, and how could stakeholders (policymakers, civil society) best

challenge tech arguments in favour of promoting prevention and health promotion, and digital inclusion for all?

- Specifically, to what extent does digitalisation pose a threat to public health advocacy and the Right to Health?
- Digitalisation may empower individuals and communities. On the other hand, it could make them more dependent on health services and promote unnecessary use of healthcare facilities. How can digitalisation empower individuals and communities in relation to their health?
- Health and well-being are multi-faceted phenomena that result from the interaction of physical, mental, social and environmental determinants. How will the different determinants of health be taken into account by digitalisation? How can we prevent reductionist approaches, such as the biomedical model, from becoming dominant?

Suggested research methods

A thorough review of the academic literature, relevant institutional reports and databases, governmental and policy documents, as well as private sector reports is envisaged, in particular those focusing on the impacts of digitalisation in other sectors and issues related to data protection and privacy, and providing "lessons learned" for the health sector. This could be supplemented with a mapping of key potential partners EPHA could collaborate with in the future to advocate in this area. If deemed advantageous or necessary by the consultant, interviews with relevant digital rights and data protection stakeholders could also be undertaken.

Ethics and risks

The study may benefit from the use of anonymity in interviews, to ensure the collection of pertinent data whilst protecting interview participants but this would be at the discretion of the researcher. No other ethical issues or significant risk is foreseen.

Framework and timetable

Subject to negotiation, EPHA envisages a final report of approximately 25 pages, to be delivered by 30 June 2019.

Interested? Please send your offer (including a brief cover letter and CV) by 23 March 2020 COB to Mr Sascha Marschang, Acting Secretary General, European Public Health Alliance at s.marschang@epha.org