Editorial

Health data governance

The coronavirus disease 2019 (COVID-19) pandemic accelerated the trend towards digitalization that is transforming health care and medicine in many fundamental ways. It is becoming clear that main barriers to building digital health systems are not technological, but institutional and organisational, thus recent national, international and global initiatives and strategic documents on health digitalization emphasise the need for strengthening governance of health data, and discuss approaches to developing data governance frameworks. Specifically,

1. In the report on digital transformation in the Organisation for Economic Co-operation and Development (OECD) countries, it is stated that such transformation relies on fundamental organisational change, which means overhauling the structures, policies and institutions that govern how systems function. The report concluded that "legal barriers and a lack of trust among patients, the public, data custodians and other stakeholders in the use and protection of data are all major hindrances, as is the lack of agreement on data standards and exchange formats both within and across countries" (OECD, 2019).
2. A recommended practical framework of health data governance in the context of low- and middle-income countries (based on experience from South Africa and India) incorporates four key domains, "covering ethical oversight and informed consent processes, data protection through data access controls, sustainability of ethical data use and application of relevant legislation". Key components of each domain are described with a special focus on their relevance to vulnerable populations in those countries (Tiffin *et al.*, 2019).
3. The Policy Brief "Health Data Governance: What's in it for Switzerland?" presents 12 broad-based recommendations for action for better health data governance on national, regional and international levels, stating that "a coordinated approach is required, from all parties, on five different governance dimensions: political, societal, ethical/legal, financial and technical". For example, at the level of society they recommend "promotion of health data literacy in society through educational programs, information campaigns and institutionalised exchanges with the population", and "creation of a democratic health data ecosystem by promoting participatory platforms for a citizen-centred use of health data". And at the technical level: "development, consolidation and application of consistent technical standards for both the national and cross-border use of health data; and improving data security by promoting research into new technologies for privacy protection". The authors also explain how Switzerland could position itself as a global health data governance hub (Knobel *et al.*, 2020).
4. The European Union (EU) is considered to be the most advanced region to promote the sharing of health data across national borders while continuing to protect privacy. In October 2020, the Finnish Innovation Fund Sitra published a working paper that provides guidelines for the future strategic use of sensitive data within European health systems. (Hämälä). It addresses ethical, legal and self-regulatory frameworks for balanced data ecosystems, discusses the current challenges and establishes a set of recommendations for a new health and well-being data paradigm. The working

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> paper also provides extensive descriptions of challenges related to the use of data: the EU's fragmented legislation, insufficient data interoperability; low digital literacy, and a lack of transparency and societal discussion that erodes trust in the actions of authorities. The creation of a European Data Space is one of the priorities of the European Commission for 2019–2025, including the health sector. The European Health Data Space is to be built on three main pillars: a strong system of data governance and rules for data exchange; data quality; strong infrastructure and interoperability. Such an approach should help to fulfil its goals: to promote safe exchange of patients' data (including when they travel abroad) and citizens' control over their health data; to support research on treatments, medicines, medical devices and outcomes; to encourage the access to and use of health data for research, policymaking and regulation, with a trusted governance framework and upholding data-protection rules; to support digital health services; and to clarify the safety and liability of artificial intelligence in health.

Despite these ongoing efforts, as it was stated at the World Health Summit, "the majority of WHO Member States. . .lack robust national data governance and digital health frameworks to ensure that the new technologies deliver sustained health benefits while protecting human rights" (World Health Summit, 2020). Thus "the inability to effectively leverage the volume and different types of available data from routine health information systems has been a notable shortcoming of the pandemic response" (Azzopardi-Muscat *et al.*, 2020).

In a call to strengthen data in response to COVID-19 and beyond the World Health Organization (WHO)-affiliated authors state that for critical decisions to be really data-driven the countries should ensure global data comparison and the secondary use of data, and as the first steps "each country needs to develop or enhance a national data governance plan that includes a clear coordination mechanism, well defined and documented data processes, the exchange of data, and a data culture to empower users" (Azzopardi-Muscat *et al.*, 2020).

We therefore turn to our readers asking any of you engaged in data governance efforts to share your progress, experience and insights. Your approaches may inspire or inform others in their data governance journeys or your national data governance plans may benefit from international reactions that publication in this journal can produce.

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Further reading

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