

EXECUTIVE SUMMARY

# Health Data Economy: Vehicles for Discovery

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The Economist Events held a roundtable sponsored by InterSystems on Health Data Economy: Vehicles for Discovery. It was moderated by Alan Lovell, senior associate for health policy and clinical evidence, The Economist Intelligence Unit, and the discussion included Samira Asma, assistant director-general, data, analytics and delivery for impact, World Health Organisation, Mark Caulfield, chief scientist, Genomics England, Joshua Denny, chief executive, All of Us Research Programme, US National Institutes of Health, and Alex MacLeod, head of global health-care initiatives, InterSystems.

The discussion examined a number of urgent questions: How will the debate between the use of patient data for commercial gain and the pursuit of the greater good continue to evolve? Who owns data in the digital age: the person represented by the data, or the entity that collects the data? What are the biggest barriers to creating a global health-data economy? How can we synchronise information systems and standardise data across a fragmented health-care landscape? What are the technical hurdles to acquiring and using data, and how do we make unstructured data comprehensible and usable?

## Digitally enhanced capabilities

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In 2021 it seems there is no such thing as too much data. That said, a number of technical barriers prevent us from effectively using them, such as interoperability and the challenges of combining structured and unstructured data. Yet there is a huge incentive to overcome these hurdles. Data can democratise access to information, and using data to underpin decision-making improves health outcomes across the board. Unfortunately the health-care sector lags behind its peers in creating a data economy. We urgently need to leverage new technologies to bring researchers to the data and create patient portals that make patients feel empowered. Natural language processing and machine learning are reshaping how we understand disease in real time. Data are also empowering life sciences worldwide to follow patients outside the traditional clinical-trial setting and understand side-effects that aren't always captured within the lab. We must also equip clinicians with tools to make sense of data, so they don't feel they are looking for a needle in a haystack. This includes creating standardised ontologies that are accepted across international jurisdictions.

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## Data regulation to protect privacy

As evidenced by Google's Project Nightingale, it is increasingly difficult for policy frameworks to keep up with the digital age and the exponential pace of innovation. The question on everyone's mind is: what makes people so nervous about sharing their health data, especially in a supposed post-privacy paradigm? There is a real need to build patient trust, foster transparency and create data-sharing models. We must help the general public understand the link between individuals' willingness to share information and improved health outcomes for the wider population. At its best, data-sharing can be likened to the difference between acquiring books to read for oneself and establishing lending libraries. However, there are concerns around the increasing ease with which individuals' identities can be gleaned from anonymised data sources. We must also pay attention to how the guardrails around data privacy have been lifted during the covid-19 pandemic. Once we return to normal—whatever that may look like—rules and regulations will need to catch up with the changes.

## Spotlight on emerging countries:

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We must help the general public understand the link between individuals’ willingness to share information and improved health outcomes for the wider population.

The United Nations is transforming itself into a modern, data-driven organisation that is able to use measurement to underpin its mandate to serve the world’s marginalised communities. The World Health Organisation (WHO) is developing the first global assessment on countries’ health-data systems. Covid-19 has shone a spotlight on the shortcomings of these systems, and the pandemic has significantly set back progress on the Sustainable Development Goals and Agenda 2030. WHO sees the crisis as an opportunity to refocus in a data-driven manner by creating a hub of open-source data, accessible in real time, to improve the world’s preparedness in the face of future pandemics. In many of these contexts the traditional issues of interoperability are compounded by a lack of checks and balances to safeguard the rights of the individual. This underscores the need to build private-public partnerships that educate people on their rights and responsibilities. There is also an imperative for better capacity-building at all levels to overcome the data drought.

In short, the use of data has the potential to benefit the entire health-care continuum, if we can improve knowledge discovery, predictive analytics and the efficiency of business processes at scale—but this means making it a global priority to overcome the technical, regulatory and investment barriers that prevent data from being a tangible public good.

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