Governing data for better health and health care

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The healthcare sector is awash with data, whose range and volume are growing exponentially. But they will sit unused in data warehouses, often from fear of being misused, unless fundamental action is taken. The OECD Recommendation on Health Data Governance can help countries in managing the risks and harnessing the benefits from health data.

Generating data is not a weakness in today's health care sector. Indeed, from doctor and hospital records to insurance claims, surveys, bio-banks, lab reports, pharmacy transactions, research studies and behavioural and environmental monitoring devices and apps, not to mention big data, there is a veritable plethora of information to draw from. But are these data being put to full and proper use for patients and health care performance?

There is arguably no other sector that generates quite as much data and, at the same time, fails to coordinate the data in effective, useful ways.

In fact, only half of the 35 OECD countries have national policies in place to address how data from electronic health records can inform clinicians, monitor disease outbreaks, conduct research and improve patient safety. Only half of OECD countries regularly link their existing health datasets to monitor health care quality.

Yet, as several countries show, better governance of healthcare data is possible and can lift performance. For instance, public reporting of health care quality indicators gives patients the information needed to identify the best health care provider, and acts as a powerful incentive for failing health care providers to change for the better.

Finland, for instance, has improved hospital services by publishing indicators about performance after hospital care, including readmissions to hospital, infections, complications and deaths. Or take Korea, which also regularly publishes indicators, focusing on the overuse, underuse and misuse of therapies.

Sweden uses health data to assess how clinical care guidelines are working, including if they are being followed by physicians and if patients' health is improving as a result. Its continuous monitoring allows action to be taken if improvement is required.

New technology is a boon to such efforts. The United States is building a rapid-response electronic surveillance system to transform how it monitors the safety of medicines and medical devices and to respond in the event of unexpected side-effects among patients taking new drugs or drug combinations, for instance.

Health data can also power the discovery of new treatments and help to personalise care in light of the unique needs of individuals. The United Kingdom now has a biobank of 500,000 adults with biological, behavioural and environmental data that can be linked to health care data. More recently, Genomics England was launched for the sequencing of 100,000 genomes among 70,000 adults, with the aim of supporting research to improve the diagnosis and treatment of diseases and advance personalised medicine.

Large health care organisations that both insure and provide care for patients have been among the quickest to use data to keep patients healthy. Clalit Health Services (CHS), the largest of the four health plan organisations in Israel, uses real-time data mining to flag elderly patients at risk of being re-admitted to hospital before they are discharged, so that they get the support and care that they need in the community.

Kaiser Permanente in the United States, one of the world's largest health management organisations, analyses patients' data to prevent illnesses, hospitalisations, deaths and waste. Clinicians and patients are reminded to practise routine preventative care, and re-fill their prescription medicines if needs be. Data helps with routine monitoring of chronic illnesses, such as blood glucose testing for diabetic patients[,] and cancer screening. By using algorithms applied to patients' hospital data in real time, clinical care teams can be alerted in advance of a serious deterioration in a patient's health. This saves resources and lives, and allows for more compassionate care.

The need for international consensus on health data governance

These are encouraging examples of how data can help policy makers improve patients' lives, but more needs to be done. Health data are personal and sensitive, and in the wrong hands, can be used to harm patients through a loss of their privacy; discrimination in areas such as health insurance or employment; and identity theft. Such data breaches and misuses weaken public trust, not just in health care providers but in policy makers, too. The rising risk of cyber attacks and the growing suite of new technologies to secure data, make the data protection environment as vital as it is challenging.

Uncertainty in the implementation of well-intended laws and policies to protect privacy and to reduce the potential misuse of personal health information has already been known to block data uses that could have helped patients. However, some countries have addressed these governance issues to improve health care. There are international and European laws, regulations and guidelines that promote the protection of privacy in the use of personal data in general, such as the OECD Privacy Guidelines and the EU General Data Protection Regulation. But the breadth and scale of data collection practices have given rise to new challenges for protection standards and procedures, such as consent to personal data collection and use. This has to be addressed, alongside complementary measures, such as education and awareness raising, skills development, and the promotion of technical measures for greater security.

The OECD Recommendation on Health Data Governance points the way forward. It represents an international consensus about the framework conditions within which health data can be

appropriately governed, so that health data processing can take place both domestically and transnationally in ways that can reduce risk and improve benefits for health systems and patients.

The Recommendation is based on 12 high-level principles, ranging from engagement and participation of a wide range of stakeholders, to effective consent and choice mechanisms to the collection and use of personal health data, to monitoring and evaluation mechanisms. These principles set the conditions to encourage greater cross-country comparison and harmonisation of data governance frameworks so that more countries are able to use health data for research, statistics and health care quality improvement.

The OECD Recommendation on Health Data Governance, which is the fruit of a multi-stakeholder effort, will be endorsed at the OECD Ministerial Meeting on Health Care in Paris on 17 January 2017. The OECD Health Committee worked alongside the OECD Committee on Digital Economy Policy to develop the Recommendation, and benefited from the advice of experts in privacy, law, ethics, health, government policy, research, statistics and IT. There were also extensive consultations with representatives from civil society, business and labour.

We believe that by following the new Recommendation, policy makers will be able to put in place systems that improve not only data collection and governance in patient-centred ways, but health care performance too. The OECD will do its part in monitoring the implementation of the Recommendation and ensuring better data governance for better lives.

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References

The 2017 OECD Recommendation on Health Data Governance and background information about its rationale and development can be found at www.oecd.org/health

OECD (2017), *New Health Technologies: Managing Access, Value and Sustainability*, available 16 January at www.oecd.org/health

OECD (2015), *Health Data Governance: Privacy, Monitoring and Research* available at www.oecd.org/publications/health-data-governance-9789264244566-en.htm

OECD (2015), *Data-Driven Innovation for Growth and Well-Being, Chapter 8: The Evolution of Health Care in a Data-Rich Environment* available at www.oecd.org/sti/ieconomy/data-driven-innovation.htm

OECD (2013), *Strengthening Health Information Infrastructure for Health Care Quality Governance: Good Practices, New Opportunities and Data Privacy Protection Challenges* available at www.oecd.org/publications/strengthening-health-information-infrastructure-for-health-care-quality-governance-9789264193505-en.htm

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