

## Executive summary

**H**Health data constitutes a significant resource in most OECD countries and it makes economic and ethical sense to use this data as much as possible: to improve population health and to improve the effectiveness, safety and patient-centeredness of health care systems. Rising levels of chronic disease and multi-morbidity; concerns about the quality and safety of patient care; the need to measure and assure value for money for investments in health; and the need to allocate health system resources wisely are all too important to leave without good evidence for decision making. Understanding the progress of the health of populations and understanding the performance and quality of health care systems requires the ability to monitor the same individuals over time, as they experience health care events, receive treatments, experience improvements or deteriorations in their health and live or die.

On 7-8 October 2010, *Health Ministers* met in Paris to discuss how to improve value in health care. In their final communiqué, they underlined the importance of better health information systems and called for more and effective use of health data that has already been collected. Ministers also noted that expanded use of health information and communication technologies (ICTs), particularly electronic health records, can help to deliver better quality of care, reduce medical errors and streamline administration. They recognised the need to reconcile the legitimate concerns of citizens to protect their privacy with the use of health data to improve health sector performance and the quality of care.

*This study indicates that national data infrastructure is improving across countries and the technical capacity to analyse and report from personal health information data assets is greater today than it was five years ago. Case studies included in this report demonstrate how many countries are linking and analysing personal health data to report on the quality and cost-effectiveness of treatments; to address underuse, overuse and misuse of therapies; to reduce variation in care practices; to assess and revise clinical care guidelines to ensure that the recommended practices are really the best practices; and to manage health expenditures.*

*In some countries, there is potential to continue and to expand data linkage studies in the future due to having reached a shared understanding with their data privacy officials of the requirements to respect principles of data privacy. This includes standardised processes for project approval, access to data and data security. There is also potential for data from electronic health record systems to be used for health care quality monitoring over the next five years. This is due to both the number of countries that plan to implement national electronic health record systems and the number of countries that consider it likely that the data from these systems will be used for some aspects of health care quality monitoring.*

There are considerable and troubling differences across OECD countries, however, in the extent to which personal health data may be collected, linked and analysed and the extent to which such data are currently contributing to monitoring population health and the quality of health care. OECD privacy guidelines provide a unifying framework for the development of national data protection legislation. However, *cross-country differences in the application of privacy principles are significant and can be attributed to differences in risk management* in the balancing of individual rights to privacy and collective rights to safe and effective health care and to a high performing health system. Many countries report legislative barriers to the use of personal health data, including enabling data linkages and developing databases from electronic health records.

Some of the countries with weaker information infrastructure have decentralised the administration of health systems and have not reached a consensus within the country of how the levels of government could work together. *Data from decentralised systems needs to be brought together to support national information infrastructure* and capacity for data use at the level of the country. A principle challenge is the lack of clarity about the interpretation of legislations concerning the protection of data privacy at the national and sub-national levels. This includes the legality of data sharing among public authorities and providing access to data for research.

The resources required to comply with legislative requirements to enable data use is a secondary problem, as is the cost of developing the technical capacity to undertake the work. Countries have provided evidence of the considerable effort they put in to protect data security and to safeguard personal health data from loss or deliberately malicious acts. Efforts were clearly demonstrated in this study related to project approval processes; internal data security; and de-identification of data to protect privacy and security measures for external researchers. Efforts to balance protection of data privacy and access to data for research are also clearly evident. Resource limitations, and not meeting expectations of timeliness, are worries among bodies that approve project proposals and among bodies that conduct data linkages on behalf of others. New forms of whole-of-government approaches to project proposal review and data linkage services are very interesting developments. Not only do these help to standardise requirements and practices for both the government and external researchers, they have the potential to be more efficient.

A particular worry across countries today is that legislative reforms that are on the horizon, or that may be stimulated due to the implementation of electronic health record systems, may turn back the clock on the progress that has been made in enabling access to and use of personal health data for research. A second worry is that a transition to reliance on data from electronic health record systems has the potential to set back the quality of national databases, by creating holes in the health care pathway or lowering the quality of the data elements, such as the coding of diagnosis. A widely reported barrier to the use of data from electronic health record systems is concerns with the quality of the data, including both a lack of coded data and poorly coded data.

A role for the OECD in the coming years is to continue to support countries in reaching the goal of strengthening health information infrastructure so that privacy-respectful uses of data for health, health care quality and health system performance monitoring and research become widespread, regular activities. *On-going monitoring of the development of health information infrastructure* will help to promote shared learning about advancements

and challenges in the development and use of health data; promote international comparability of data and data linkages; and uncover new opportunities for the development of internationally comparable indicators of the quality of care.

Another important step will be to *support countries in reducing unnecessary obstacles to data use* that can arise from differences in legislations regarding the protection of health information privacy and differences in the interpretation of what is necessary and helpful to assure that patients' privacy rights are respected in the conduct of health monitoring and research. A risk classification of data and data uses, to identify cases of higher risk to patient's information privacy and to associate recommended data privacy protection practices that will enable even very sensitive data to be used for research and monitoring, would support countries in developing privacy-respectful uses of data to improve health, health care quality and health system performance.



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