

## Chapter 1

# Strengthening health information infrastructure matters

*Health data constitutes a significant resource in most OECD countries that could be used to improve population health, the quality of health care and the performance of health systems. Well-intended policies to allay concerns about breaches of confidentiality and potential misuse of personal health data may be limiting data use. In 2010, Health Ministers called for OECD support to strengthen health information infrastructure.*

*In 2011/12, 19 countries participated in an OECD study to better understand the extent to which countries develop and use personal health data and the reasons why data use may be problematic in some. In 2011/12, 25 countries participated in a related OECD study to describe the development and use of personal health data from electronic health record systems, including barriers and facilitators.*

*This chapter describes why the privacy respectful use of personal health data is so important to strengthen information infrastructure for monitoring and research to improve health, health care quality and health system performance. It provides an overview of the issues to be examined in the next chapters of this report, as well as background information about how the studies were conducted.*

The statistical data for Israel are supplied by and under the responsibility of the relevant Israeli authorities. The use of such data by the OECD is without prejudice to the status of the Golan Heights, East Jerusalem and Israeli settlements in the West Bank under the terms of international law.

**H**ealth 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. Data to measure, monitor and compare performance are central to the assessment of both the health of populations and the quality and efficiency of health care services. Regional, national and international reports on health and health care are entirely dependent upon monitoring policies and investments in data infrastructure that either facilitate or restrict data and analysis (OECD, 2011). 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. It also requires understanding the distribution of health and health outcomes across different groups in the population and understanding variations in care quality and health outcomes.

This work has a few very important prerequisites. First it depends on the collection and storage of data at the level of individual patients (for an entire population of patients or for a representative sample). The most common sources of health data are registries, administrative data, population surveys, patient surveys and clinical records. Second, it relies on the capacity to be able to follow individual patients across the care continuum and through different health events to measure change. Following patients through different health and health care events often requires the linkage of patient records across databases. This is because few databases have all of the needed information. This type of follow-up permits understanding of, for example, adverse drug reactions, medical errors, poor primary health care, deaths following treatments, and ineffective treatments. The capacity to construct accurate data to understand the pathways of patients through the health care system and to assess the health outcomes and costs that result is increasing rapidly. The health care sector is undergoing a significant transformation toward the adoption and use of information technologies. The computerisation of health care records and the development of capacity to exchange records to construct patient health care pathways is a promising new frontier for the advancement of measurement of the quality, efficiency and effectiveness of health care.

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. They 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 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. In 2011 and 2012, the OECD undertook this in-depth study of the development and use of personal health data to understand patient pathways and outcomes via the linkage of personal health records across multiple datasets within countries and across multiple countries; and via the development and use of data from electronic health record systems.

The implementation of electronic health record systems amplifies concerns about the protection of confidentiality of data and privacy intrusion because EHR records can contain longitudinal patient histories and are meant to be transmitted across a computer network. Restrictions on content, storage and use of these records are necessary to mitigate risk of misuse. However, as EHR systems replace traditional health care databases, it is essential that secondary uses of data to monitor health care quality are given consideration. Otherwise, rather than improve monitoring of health care quality, stagnation and even deterioration in ability to monitor quality could occur over time.

While national implementation of EHR systems is still relatively new, the use of other forms of personal health data to report on patient health care pathways and outcomes is technically possible in most countries, due to advancements in detailed individual-level data and computer processing capacities. There is, however, evidence of significant cross-country variability in the extent to which these data resources are currently being used for health and health care monitoring and research.

Well-intended privacy and confidentiality decisions, which aim to allay concerns about breaches of confidentiality and reduce potential misuse of personal health information, may have made a contribution to this variation. In 2008, the Working Group on Data Protection of the EU NCA observed that diverging opinions on how to interpret the EU Directive on Data Protection (Directive 95/46/EC) and poor transposition into national data protection laws appeared to be a significant barrier for European public health monitoring and research. The Group recommended that best practice examples should be developed to provide guidance on the collection of high quality health data and that the privacy requirements be clarified and harmonised across countries (Verschuuren et al., 2008). Further, the group concluded that awareness of data protection issues among public health experts and researchers should also be promoted. Many other individuals and groups – especially medical researchers, public health officials, and health care delivery organisations – have countered that overzealous or misdirected privacy protections are thwarting efforts to use information to improve patient care and public health.

To be useful for the assessment of the quality of care, health and health care data collections need to be organised in a systematic and efficient way, to be structured to support linkage across data sources, and to be accessible. At the same time, confidentiality of the data needs to be protected and privacy rights addressed (OECD, 2010). In May 2011, the OECD Health Care Quality Expert Group proposed undertaking this in-depth study to better understand the challenges, the opportunities and the practices in the use of data to monitor and describe pathways of care and health care outcomes to enable health care quality and health system performance monitoring and research.

## Issues examined in this report

This report focuses on country experiences in the development and use of data to understand patient pathways and outcomes via the linkage of personal health records across multiple datasets within countries and across multiple countries; and via the development and use of data from electronic health record systems. It explores the extent to which there are cross-country variations in data use and the reasons for them and proposes next steps for international action.

*Chapter 2* presents case studies of policy-relevant uses of personal health data to improve health and health care quality and efficiency that were selected by countries as representing best practices in the protection of data confidentiality, respect for patient privacy and privacy legislations, excellent data security, using high quality data and having a sound research methodology.

*Chapter 3* provides information on the status of health information infrastructure today including the availability of personal health databases at the national level, the sharing of data across national public authorities, national infrastructure for data linkages and analysis, regional and health care network infrastructure for data linkages, and regular uses of linked data for national health and health care monitoring and research.

The development and use of data from national electronic health record systems is presented in *Chapter 4*. This includes current uses of electronic records in physician offices and hospitals; national plans to implement electronic health record systems; a description of implemented national systems; the development of minimum datasets; the use of structure and terminology standards to code data; the status and technical challenges of database creation from electronic health records; and current uses of data from electronic health records including monitoring public health, patient safety and health system performance and conducting research.

*Chapter 5* introduces issues regarding the protection of patient privacy in the collection and use of personal health data. It describes how cross-country variation in data use relates to differences in risk management in the balancing of individual rights to privacy and collective rights to patient safety and high performance health care. OECD guiding principles for the protection and transborder flow of personal data are presented and cross-country differences in the application of these principles are discussed, including the conduct of data linkage activities and the development of data from electronic health records.

Aspects of the governance of data linkages and the provision of access to data are discussed in *Chapter 6*. This includes country experiences in the de-identification of data to protect the privacy of individuals; the development of secure facilities for access to data with high re-identification risk; project approval processes for data linkage projects; data security within public authorities holding data; data protection when public authorities provide data to external researchers; and governance of multi-country studies involving personal health data.

*Chapter 7* provides country experiences in the governance of electronic health record systems and the use of data from these systems. This includes the development of national bodies to oversee national EHR implementations, the use of legal requirements to adopt EHRs or adhere to standards, the use of incentives and penalties to encourage quality in the use of EHRs, concerns with data quality and the use of data quality auditing,

and the engagement of third parties to assist with building databases, de-identifying data and approving applications for data access.

Views of study participants regarding the strengths and weaknesses of their national information infrastructure and the potential for this infrastructure to support data use over the next five years are presented in *Chapter 8*, followed by conclusions and recommendations for international actions to support countries in their efforts to strengthen information infrastructure in *Chapter 9*.

## Study method

A mail-back questionnaire sought information about the general environment in each country for the secondary use of personal health data as well as specific case studies. The questionnaire was sent to the members of the OECD Health Care Quality Indicators Expert Group in July 2011 and responses were received from 19 countries from September 2011 through to March 2012. Countries participating in the survey include Australia, Belgium, Canada, Denmark, Finland, France, Germany, Israel, Japan, Korea, Malta, Norway, Poland, Portugal, Singapore, Sweden, Switzerland, the United Kingdom and the United States (see Annex A).<sup>\*</sup> Members of the Health Care Quality Indicators Expert Group represent the 34 member countries of the Organisation for Economic Co-operation and Development as well as a number of non-member countries who are participating actively in the HCQI project.

As part of this questionnaire, contact persons were identified who were knowledgeable about the general environment for secondary use of personal health data involving data linkages and multi-country studies. Experts with knowledge of national level studies, as well as regional, state and health care network specific studies were identified. Structured telephone interviews were conducted with 31 selected experts from September 2011 to March 2012 (see Annex B).

A second mail-back questionnaire sought information about progress in the development of electronic health record systems and the specific elements of the design that relate to the ability to extract high quality data from these records to monitor and report on health care quality. The questionnaire was sent to the members of the OECD Health Care Quality Indicators Expert Group in February 2012 and responses were received from 25 countries from March to August of 2012. Countries participating in the survey include Austria, Belgium, Canada, Denmark, Estonia, Finland, France, Germany, Iceland, Indonesia, Israel, Japan, Korea, Mexico, the Netherlands, Poland, Portugal, Singapore, Slovakia, Slovenia, Spain, Sweden, Switzerland, the United Kingdom and the United States (see Annex C).

<sup>\*</sup> Italy participated in the telephone interview part of the study.

### Box 1.1. Key concepts

#### Secondary use of personal health data

Health data is often originally collected for administrative purposes or for direct patient care. Re-use of this data for purposes other than those for which it was originally collected is considered a secondary use. Some of the most common secondary uses of health data include:

- identifying the causes of disease, the prevalence of risk factors and identifying populations at risk;
- protecting public safety, especially with regard to infectious disease, but also in relation to prescription medicines, medical devices and environmental hazards;
- needs assessment, monitoring and evaluation of services, with a view to providing an optimum performance of health care systems; and
- improving the quality and safety of care in hospitals, practitioner's offices, clinics and other health care settings.

Health data is personal when it is collected and stored at the level of individual patients or persons or can otherwise be related to an identified or an identifiable individual. Personal health data is needed to track events over time or across different health care settings and to investigate the potential role of risk factors in the development of disease or the effectiveness of treatments. Often such analysis requires the linkage of personal health data across two or more data sets. Linkage occurs when records from the same patient, or the same person, in two or more different databases are merged together, creating a more complete health biography. An example would be linking patient records in a hospital database to any death records for the same persons in a mortality database, in order to identify patients who died following treatment (see glossary).

Public registries, administrative databases and clinical records, including electronic health records, are all important sources of personal health data where analysis and dissemination of results are a secondary use of the data. Other important sources of health data include population and patient surveys and population censuses or registries.

#### Electronic health records

There are varying interpretations of an appropriate definition of electronic health records. The OECD has been working toward the benchmarking internationally of information and communication technology (ICT) in the health sector. The benchmarking project aims to elaborate internationally agreed upon definitions of ICTs through a development process that began recently.

For the purposes of this study, electronic health records (EHRs) were defined as the longitudinal electronic record of an individual patient that contains, or virtually links together, records from multiple electronic medical records (EMRs) which can then be shared (interoperable) across health care settings. It aims to contain a history of contact with the health care system for individual patients from multiple organisations that deliver care.

For this study, an electronic medical record (EMR) is a computerised medical record created in an organisation that delivers care, such as a hospital or physician's office, for patients of that organisation. EMR are provider or organisation centric and allow storage, retrieval and modification of patient records. In some health care settings, the same type of record may be referred to as an electronic patient record or EPR.

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