Chapter 4

National electronic health record systems

Countries are moving forward to develop databases from electronic health records for monitoring and research. Twenty-two of twenty-five countries report a national plan or policy to implement electronic health records and 20 report starting its implementation. Eighteen national plans include the secondary use of the data. Thirteen countries are using data from electronic record systems to monitor public health, eleven countries to conduct health research and nine countries to monitor patient safety. Barriers to creating and analysing databases from electronic health records reported by countries include concerns with current legislative frameworks, particularly as they apply to data privacy protection (16 countries); problems with the quality of data within EHRs (14 countries); and resource constraints to database creation (nine countries) and to the de-identification of data to protect privacy (seven countries). Data quality concerns include a lack of clinical terminology standards; improper coding; missing data; and variable quality across health care providers.

This chapter reports findings from the 2011/12 OECD study of 25 countries regarding current uses of electronic records in physician offices and hospitals; national plans to implement electronic health record systems; implementation of 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 public health, patient safety and health system performance monitoring.

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.

Electronic health record systems in some countries enable patients to have an electronic record of their key characteristics and health concerns, as well as their history of encounters with the health care system and the treatments that they have received from a variety of health care providers. This record can then be shared with new health care providers to support provision of the most appropriate care. The existence of such records opens a promising new frontier for advancing patient care, in the same way that advancements in the use of information technologies have revolutionised most other industries.

The goals of such systems include improving the quality and safety of care for individual patients, as well as facilitating optimal care pathways and promoting efficiency in the use of health system resources. It is not difficult to see the benefit of sharing records to avoid medical errors. This is particularly evident during emergencies; when patients may be unable to speak for themselves and thus unable to alert health professionals to their underlying medical conditions, current medications and allergies. It is also evident that when multiple physicians and professionals are treating the same patient, sharing a patient's medical history would help to prevent adverse health outcomes from inappropriate treatment combinations and would help to avoid unnecessary repetition of clinical tests.

The ideal electronic health record system would have the attributes of accuracy, completeness, comprehensiveness, reliability, relevance, timeliness and accessibility. These are also the attributes of a well-functioning statistical system. This is not surprising given an electronic health record system is essentially the same: a very large and complex system that is gathering, compiling, organising, and reporting data.

As countries move toward realising a national electronic health record system that meets all of these desirable attributes; there is an increasing possibility of benefiting from the system to build databases to monitor and to conduct research to improve the health of the population and the quality, safety and efficiency of health care. At the same time, wherever the implementation of the electronic health record system is inadequately addressing one or more of these desirable attributes; it may be difficult or impossible to benefit from the system to evaluate whether or not health care quality and safety are improving.

The scope of the effort to implement national electronic health record systems is daunting for governments in all countries. Essential elements include development of national plans; enactment of new legislation to launch the effort or to manage particular elements, such as the protection of information privacy; development of governance mechanisms; development of standards for both semantics and for the interoperability of electronic health records across different health care settings; engagement of regional authorities, insurers and health care providers in the effort; liaison with private industry for infrastructure and software; development of certification for software vendors; training efforts and public education; and considerable budgetary support.

It is perhaps not surprising that, as a result of the difficulty of transforming an industry as complex as the provision of health care, early work toward electronic health care system development often did not include consideration of the potential of electronic health record systems to support national monitoring and research to improve population health and the quality, efficiency and performance of the health care system.

The challenge countries face however, is that assessment of the usability of electronic health records for statistical purposes cannot wait until after the implementation of electronic health record systems. This is because decisions taken during the implementation may result in a system that is poorly suited to the generation of high quality and useable statistics. The better course of action is to critically evaluate the electronic health record system plan and its implementation today, so that the deployment can yield the data needed to advance population health, efficient and effective health systems and patient safety tomorrow.

Use of electronic medical and patient records in physician offices and hospitals

All countries participating in this study (see Annex C) reported that at least some primary care physician offices, medical specialist physician offices and hospitals are capturing information on patient diagnosis and treatment electronically (Table D.11). For this study, an electronic medical record (EMR) or electronic patient record (EPR) 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 and EPR are provider or organisation centric and allow storage, retrieval and modification of patient records.

Most countries were able to report an estimate of the proportion of primary care physician offices capturing patient data electronically. Twelve countries reported high penetration of electronic medical records among primary care physician offices, with 80% or more having adopted EMRs. Many countries were also able to report an estimate of the proportion of medical specialist physician offices capturing patient data electronically. Generally, countries with a high penetration of use among primary care physician offices, reported large proportions of medical specialist physician offices capturing patient data electronically. Many countries were also able to report the proportion of hospitals capturing in-patient diagnosis and treatment information electronically. Among them, nine countries reported all hospitals using electronic patient records including *Austria, Denmark, Estonia, Finland, Iceland, Israel, the Netherlands, Sweden and the United Kingdom*. Annex E provides additional information about the adoption and use of electronic medical and patient records in the countries participating in this study.

National plans and policies to implement electronic health records

Most countries have a national plan or a national policy to implement electronic health records* (Tables D.12 and D.13). Such plans commonly include elements of governance of the process and the establishment of standards. Countries are divided, however, on whether or not current plans extend to secondary uses of data from these systems. More than half of the countries participating in this study have included public health monitoring (15 countries); health system performance monitoring (15); and supporting physician treatment decisions by enabling physicians to query the data to

* Table D.13 provides web-links to plans or policies to develop national electronic health record systems.

inform themselves about previous treatments and outcomes for similar patients (14). Many countries also intend to benefit from the data for research (13); patient safety monitoring (12); and facilitating and contributing to clinical trials (10), such as enabling the follow-up of clinical cohorts to measure treatments and outcomes over time.

Eight countries, *France, Indonesia, Korea, Mexico, Poland, Singapore, Slovakia, and the United States,* have a national plan or policy to implement electronic health record systems that includes all of the secondary uses of personal health data investigated in this study.

Korea reported that the implementation of a national EHR project was part of a 2005 National Health Information Infrastructure Plan under the provisions of the Framework Act on Health and Medical Services. The availability of budget to execute the plan was an initial problem, however dimensions of the plan are now underway including computerisation of public health and medical institutions; development of a national health information infrastructure master plan; proliferation and management of information standards and enactment of necessary legislation; development of a national health information system; and development and implementation of a pilot project for a national e-health service. A national interoperability roadmap was established for *Mexico* in 2008 with implementation phases underway. The roadmap is updated annually.

Five countries, *Belgium, Finland, Estonia, Portugal and the United Kingdom* report that their national plans or policies will include most of the secondary uses of personal health data explored in this study.

Belgium reports that public health monitoring is not yet incorporated into EHR plans at the federal level; however, it is already part of the functionalities of certified EHR systems. The semantic interoperability layer will need to be completed for wide adoption of public health reporting and for the use of electronic records to facilitate and contribute to clinical trials. Similarly, patient safety monitoring will be developed but priority is currently placed on the deployment of the EHR system and developing trust in it. Data from EHR systems will contribute to supporting physician treatment decisions through use cases, such as for nephrology. The monitoring of health system performance and research to improve patient care, health system efficiency or patient health are usually undertaken with social security and sentinel site databases rather than data from electronic health records.

Finland has an established set of national registers that are used for all of the secondary data uses included here. There is already implementation of systems to extract data from the electronic health record system to update the registers. To support physician treatment decisions, however, there are local and regional applications but no national level data extraction for this purpose. National plans, however, include the implementation of this feature in all regions. Both national registers and local and regional EHR systems are used for research. At the national level, however, current legislation does not permit direct access to records in the national EHR system for research purposes. There are policy discussions to consider revisions to the legislation to enable this research.

In the *United Kingdom*, England reports that virtually all of the secondary analysis activities are included in the EHR plan. The tracking of cohorts or groups of patients to facilitate clinical trials is not part of the original plan but it was added as an activity later. Scotland reports that it is likely that data from EHRs will be used to support most of the secondary analysis activities included in this study; however, they are not all explicitly mentioned in the high level strategy.

Portugal is planning to undertake public health monitoring, monitoring of health system performance and patient safety, and research to improve population health and health system performance through analysis of data from electronic health records. Concerns with the quality of the information within the EHR system have lead to a decision to not plan to use the data to facilitate or contribute to clinical trials or for physician queries to support treatment decisions.

Iceland and Slovenia have plans to use data extracted from electronic health records for public health and health system performance monitoring. In *Slovenia*, other secondary data uses explored here are expected to be in scope for inclusion when more detailed national plans are drafted. The national EHR has not yet been implemented in Slovenia and currently only local EMRs are in place. In *Iceland*, national disease registries that are not based on EHR data are currently used for research and surveillance purposes.

In the primary care sector in *Denmark*, data from EHR systems is used to support physician treatment decisions by enabling examination of treatments given to similar patient groups. There are no other secondary uses of data from EHR systems. Databases in Denmark are prepared from completion of forms or extraction of data from health information systems and are used for all of the secondary purposes examined here. For clinical trials, the trial will collect its own data or obtain data from local area surveillance systems.

Israel, Japan, Spain and Switzerland have not included secondary uses of data from electronic health records within their national development plans or policies.

Canada does not have a national plan or policies for secondary data use from electronic records. Planning to increase secondary uses of data from EHR systems within provinces and territories has been underway, including efforts to develop a shared vision for secondary data use in Canada and efforts to expand the scope of the national EHR funding plan to also include secondary uses of data. No uses of data from the national EHR system were reported for *Israel*. At present, most secondary data uses explored here are undertaken by analysing data from electronic medical records of hospitals and HMOs.

Japan introduced a personal EHR called "My Hospital Everywhere" in 2010 to be implemented by 2013. This EHR is intended only for the personal use of patients and their health care providers and therefore is not available for secondary analysis. The national plan aims to promote the effective use of national insurance claims data to improve quality and efficiency and enables this patient-level data to be used for research purposes under strict conditions. The national plan also calls for the development of a multi-hospital data base entitled the "Japan Sentinel Project" that will be developed from electronic patient records in order to ensure drug safety.

In *Spain*, autonomous communities develop regional policies for their own EHR systems. Co-ordination efforts ensure that regional developments support national plans. There are no plans to extract data from electronic health records for analysis. Spain has established hospital and primary care databases, health system activity registries, safety events registries, and special studies for monitoring and research.

Switzerland has placed first priority on the establishment of the national EHR and secondary uses of data may be a next step. This will be explored by the Swiss Federal Statistical Office which is responsible for health care statistics with anonymised data.

There is no national plan or policy to implement EHRs in *Germany, the Netherlands or Sweden*. *Germany* noted governmental support for e-health services, such as the

introduction of an electronic health card and an associated telematic infrastructure. In Germany, however, health care providers are mainly responsible for the design, implementation and use of electronic health records following medical guidelines and quality requirements. The *Netherlands* reported that the Ministry of Health has put much effort into developing a national law that would enable the creation of a national exchange point for the sharing of electronic patient information. Although the initiative was already far developed, the Senate voted unanimously against the law in 2011. As a result, there is no national policy currently; however, several stakeholders intend to re-launch the initiative on an opt-in basis. *Sweden* has a decentralised health care system with 20 county councils and 290 municipal councils responsible for providing adequate care services and for developing, quality-assuring and financing all care activities. While the Swedish e-Health Strategy co-ordinates national EHR implementation, county and municipal councils are responsible for their own EHR implementations.

Implementation of a national electronic health record system

Twenty countries participating in this study have implemented or are starting to implement a national electronic health record system. In accordance with the definition used in this study, such a system refers to the longitudinal electronic record of individual patients that contains or virtually links together records from multiple electronic medical and patient record systems which can then be shared (interoperable) across health care settings. It aims to provide a history of contact with the health care system for individual patients.

Fourteen countries are aiming toward a system where patient's electronic records may be both shared among physician offices and between physician offices and hospitals; and where these records can exchange information about current medications, laboratory test results and medical imaging results. These systems can result in a unified longitudinal patient record. Six countries are restricting the scope of the national electronic health record to only some of these dimensions.

Fifteen countries (Austria, Estonia, Finland, France, Indonesia, Israel, Poland, Portugal, Japan, Singapore, Slovakia, Spain, Sweden, Switzerland and the United Kingdom) reported implementing either a single country-wide electronic health record system or an integration of regional EHR systems permitting some records to be exchanged nationally. The national EHR implementation is new among all of these countries, with only a few countries reporting a small proportion of practices having implemented the national EHR within the past four years. The exceptions are Estonia, where implementation also began within the past four years, but where a majority of physicians offices and hospitals have implemented the national EHR system and Israel, where sharing of electronic records was established a decade ago within certain HMOs.

Japan's "My Hospital Everywhere" project enables patients to store and access their electronic medical records which may then be retrieved by health professionals anywhere in the country. The Japan Sentinel Project networks a dozen large medical centres as well as large national hospital chains with 40-50 hospitals to share electronic medical records to monitor drug safety.

Sweden's national electronic health record system is a shared national patient summary record. Similarly, *Israel's* national system will allow HMOs and Hospitals to share summary records on admission and discharge.

Austria is introducing a country-wide system involving virtually linked data through the use of IHE (Integrating the Healthcare Enterprise) recommendations to facilitate interoperability.

Singapore is implementing a single country-wide EHR system to achieve its vision of "One Singaporean, One Health Record". A document exchange solution EMRX was implemented in 2004 which enabled the exchange of some medical information across public health care institutions. The National EHR (NEHR) is a more robust system which stores data in structured formats and is standards-based. It builds upon existing systems and allows extensions beyond the public sector coverage. It extracts and consolidates into one record, clinically relevant information from patients' encounters across the public and private health care system throughout their lives, and enables authorised health care providers to improve the overall quality of care rendered to patients at different points of care. *Portugal* is developing a single country-wide system called the Portuguese Health Record (Plataforma de Dados de Saude, PDS). Data exchange between hospitals and physicians is already in place in the Northern Region which covers about 45% of the population. The system shares information across levels of care and builds an evolving patient summary record over time that is controlled by the patient's general practitioner. This system includes all of the dimensions of record exchange investigated here (see Table D.14). The remaining four regions will be connected in 2012.

Slovakia aims to complete nation-wide implementation by 2014. *Indonesia* has introduced an information exchange among six hospitals and intends to extend this implementation nationwide.

Switzerland reported undertaking a step-by-step integration of regional EHR systems in the direction of achieving a national EHR system in the future. A new national law sets certification requirements that must be respected by communities of health care providers in order for them to share records with other communities. The law aims to ensure that regional systems will be interoperable.

The *United Kingdom* has different electronic health record systems across member states. England is implementing a single summary record for emergency care. About one-quarter of providers have implemented the English EHR system over the past four years. Scotland is making available a single summary record from primary care physicians for use in medical emergencies. Scotland also makes some systems available to its regions, but it is a regional decision whether or not to implement them. Scotland reports that each system has a different implementation date and participation rate.

Poland reported beginning to implement a patient account as a single system accessible to patients over the Internet that would include laboratory test results and prescription medicines. For other dimensions of electronic health record implementation, the regions are organising the effort.

Spain is establishing a central national node as a hub for messaging services between health services providers in each territory. Territorial nodes act as concentrators of EHR contents from diverse systems. The health care authority in each territory will manage its integration platform (node). Nine document types have been identified for inclusion in the national system, which is only a portion of the documents that may be available within local systems.

In *Denmark,* the implementation of electronic health records is a regional responsibility. The regions have a goal of achieving five coherent EHR landscapes. Regional

EHRs will be able to access read-only information from national data sources. This system will be implemented from 2012 onward. Some features of the Danish EHR system have been implemented, including physician receipt of laboratory test results (85%), sharing of medications information among physician offices and hospitals (50%), and physician sharing of medications information with other physician offices (30%).

Similarly, the implementation of EHR systems is a provincial and territorial responsibility in *Canada*. Each of Canada's 13 provinces and territories has an electronic health record deployment project underway. Deployment ranges from 0-100% as defined by a mix of six core elements of electronic health record systems. Canada Health Infoway estimated that at least 50% of Canadians had these core elements available to them as of March 2011. Some provinces and territories provide primary care physicians with access to electronic repositories of patient information about laboratory tests, medications, and digital images and some receive discharge and clinical notes from hospitals.

In *Belgium*, the exchange of data is organised at a regional level. Belgium is using a federal reference directory, a national unique patient identifying number and common standards and rules to ensure the interoperability of regional systems and to achieve national coverage. Some health care providers have already implemented the regional systems. The sharing of information within regional EHRs is recent with some functionality implemented one year ago.

In *Iceland*, there is not yet a national electronic health record system. Patient data is exchanged among health care providers and, for laboratory test and medical images, within each health region, excluding the capital area.

In *Korea*, there is no national electronic health record system. Public health centres however, have been adopting the electronic health record system developed as a result of the Public Health and Medical Institution Informatisation Project over the past few years and are now at 100% participation.

In *Mexico*, the four main health care institutions, providing primary and tertiary care, have electronic patient records. A master patient index for three of these institutions is under development in 2012. The architecture of an interoperability platform was designed in 2010 but is not yet implemented. States and other institutions within Mexico have plans to implement interoperability mechanisms.

Minimum data sets

Countries were asked if their national EHR plan included the identification of a defined set of data that could be shared among physicians treating the same patients. This dataset may be called a "minimum data set" and it is intended to support standardisation and sharing of a core set of key information. The existence of a minimum dataset also has important implications for a country's ability to extract consistently defined data from electronic health records to build a national database, should they wish to do so.

Eighteen countries reported having defined a minimum data set for the sharing of electronic patient data (Table D.15). For all of these countries, the minimum dataset would contain patient identifiers, such as a unique patient identifying number and/or a set of identifiers, such as names, addresses and dates of birth; clinically relevant diagnostic concerns, such as chronic conditions and allergies; unique identifiers for health care providers; and patient demographic information, such as dates of birth and sex. Seventeen countries will also include current medications and 16 will include patient clinically

relevant procedures, such as surgeries, screening tests and laboratory results. Nine also reported including patient clinically relevant physical characteristics, such as body mass; and ten reported including clinically relevant behaviours, such as smoking and alcohol use. Fewer countries indicated including patient socio-economic data or clinically relevant psychosocial or cultural issues, such as caregivers or stressful events.

Denmark implemented a minimum dataset in conjunction with the EU epSOS project in 2010. It is a common electronic journal for primary and secondary care. This e-journal will include ICD10 coded diagnosis, episodes of care, and treatments, including coded surgery interventions. All patients in Denmark currently have at least some of the elements of the minimum dataset in their electronic record. There is only one minimum data set specification. It is, however, in pilot testing in 2012 and may be subject to change. Also being pilot tested this year is an electronic journal that patients can view. It will contain all of their health care contacts, laboratory tests and medications.

Denmark is also piloting in 2012 the development of a common medications list for patients that will be exchanged among physician offices and hospitals through a common medications database. A database of medications dispensed by private pharmacies (outside hospitals) is already accessible to physicians and hospitals. In Denmark, information on diagnosis from hospital discharges and outpatient clinics is coded using ICD10 and collected in a national repository that is accessible to all hospitals and patients.

Switzerland reported first specifying a minimum dataset in 2009. In addition to the minimum dataset content explored in Table D.15, Switzerland includes within its minimum dataset: blood group, date of transfusion, immunisation status, dates of transplantation, allergies, diseases and disabilities, an address to contact in case of emergency and information on the patient's insurance provision. Fully 90% of patients have an electronic record containing this minimum dataset which is related to the adoption of smart cards.

Singapore first specified a national minimum dataset in 2011; however, in a short time it has been able to implement the dataset for 90% of patients. *Belgium* implemented a minimum dataset in 2003 and about 5% of patients currently have an electronic record containing this dataset. *Indonesia* reported a minimum dataset that was specified in 1996. There is no data on the proportion of patients with an electronic record containing these dataset elements. These three countries all report that there are no other minimum dataset specifications in use.

In the *United Kingdom*, England reported establishing a minimum dataset called the national summary record for the sharing of patient information electronically to support unscheduled (emergency) care. The NHS number will be used to uniquely identify patients. While patient demographic information is not included in the summary record, it is possible to look up the information from the national demographics file. Patient clinically relevant procedures are a possible future addition to this summary record. This minimum dataset was first specified in 2006 and 25% of patients now have a summary record. This minimum dataset and transactions standards for it have been agreed upon for England and there are no other minimum dataset standards in use.

Scotland has specified 14 sets of information to be made available through a clinical portal. Only one minimum dataset has been agreed upon for all patients, which is a patient summary dataset to support emergency care. The minimum dataset was first specified in 2004. Other datasets are published in the NHS data dictionary and are also specified by

professional bodies for disease-specific or specialty domains. Scotland is focussing on clinical record headings to define how content can become interoperable.

Finland specified a minimum dataset for sharing information that is planned to be implemented by law by 2014. The current implementation level differs across the country. In addition to the elements identified in Table D.15, Finland has also introduced additional information, such as health risk factors, within its minimum dataset. While socio-economic data is not included in the minimum dataset, it can be linked to the minimum dataset from other data sources when this information is required.

A minimum dataset was first specified by the Clalit HMO in *Israel* in 2002. This minimum dataset was then adopted nationally in 2012. At present, about one-half of patients in Israel have an EHR containing this minimum dataset. *Estonia* first specified a minimum data set in 2008 and reports that 68% of patients have an electronic health record containing this minimum data set.

In the *United States*, there is no single "minimum dataset" that all providers would be required to capture for the purposes of populating an EHR and there are different specifications in use. Health care providers who adopt a certified EHR system, however, may qualify for a financial incentive associated with meeting "minimum use" requirements in accordance with the 2010 HITECH Act. Such certified systems use an established patient summary record format for the purpose of supporting patient transitions among different health care providers. The elements within the summary record relate to standards of care recognised internationally. The information on procedures (such as surgeries, screening tests and laboratory results) included in a patient summary record will vary by patients and their clinical circumstances. In the United States, information on patient socio-economic characteristics is considered valuable for population health and health care decision making, but there is some cultural sensitivity to their inclusion in the patient summary record. There is no data on the proportion of patients with a summary record.

Canada recommends that provinces and territories adopt standards for specifications of a minimum set of data that are based on the internationally recognised HL7 standard for the exchange of information among physicians and hospitals that was recommended in 2002; and pan-Canadian standards for the content of primary health care electronic medical records, that were recommended in 2009. Adoption of these standards by the provinces and territories is voluntary and each province or territory defines their own content for their minimum dataset based on business requirements and the data available from existing EMR systems vendors and hospital information systems vendors operating within their jurisdiction. In addition to promoting interoperability and vocabulary standards, Canada Health Infoway is developing toolkits for both vendors and jurisdictions to use when implementing and managing differences in standards and terminologies. There is no data yet on the proportion of patients covered by a minimum dataset adhering to the standards.

Korea reports the specifications of a minimum dataset are shared among public health centres. This dataset was established in 2008 and the minimum dataset has been fully implemented among these centres, covering 70% of patients. *Mexico* specified the minimum dataset at a national level in 2010; however, the large federal institutions were already using their own minimum information specifications. They are now working toward adoption of the common national specifications. These main institutions estimate

that about 30% of patients have an electronic record meeting the national minimum information specifications.

Spain specified a minimum dataset in 2010 and the data set has been incorporated within the electronic health records of an estimated 27% of patients. In addition to the data elements noted here, Spain includes other items within the minimum data set. These include information on risk of domestic violence or child abuse; advanced directives; participation in clinical research studies; and an option to restrict access to clinical information. A minimum dataset was also established for *Sweden* in 2010 and less than 10% of patients were reported to have an electronic health record containing this dataset at the time of the survey. A minimum dataset was recently specified in Portugal (2012) and no patients' electronic records contain it yet. There are no other minimum dataset specifications in use.

The minimum dataset for *Slovakia* is being developed in 2012 and a pilot project to implement it will be part of the second phase of eHealth implementation beginning in 2013. There are no other minimum dataset specifications in use. *Austria* has not yet developed a patient summary record, although it is being designed. There are currently other specifications for minimum datasets in use. *Japan* has also not yet developed a minimum dataset. A taskforce of the IT headquarters within the Cabinet proposed in May 2011 to introduce a minimum dataset within the next few years. The proposed minimum dataset would contain all of the items included for Japan in Table D.15.

In *Poland,* the National Centre for Health Information Systems (CSIOZ) is responsible for developing propositions for the minimum dataset which is planned to be specified by 2014. CSIOZ intends to implement results and standards of the EU epSOS project and is awaiting decisions of the EU Digital Agenda for 2020. Poland does have a current problem of multiple specifications for a minimum dataset, including data required by the NHF and also other datasets connected with specific health problems (such as cancer and mental diseases). The National Centre for Health Information Systems is working to solve problems of inconsistency of regulations and requirements.

France reports no minimum dataset specification as part of the national electronic health record and there are also no other sets of minimum dataset specifications in use. In France, patients specify the elements of their electronic documents to be shared. There is also no minimum dataset in *Germany*. Datasets are defined by organisations of health care professionals and are mostly specific to the care situation. There are, however, some similarities across datasets in terms of patient identification, and reporting diagnosis and medications used in communication of reports and discharge letters. The probable existence of more than one specification for a minimum dataset is not viewed as a problem. *Slovenia* has also not specified a minimum dataset.

Structured data elements within electronic records

One of the early worries about the usability of data within electronic health records for patient care was the use of free flowing text. Early implementations of electronic records provided physicians with essentially an electronic means to record clinical notes. As interest in sharing records grew, so did the need to ensure that health care providers could access, and quickly and accurately interpret, a record created by another health care provider. The use of structured data entry that follows clinical terminology standards emerged as a solution.

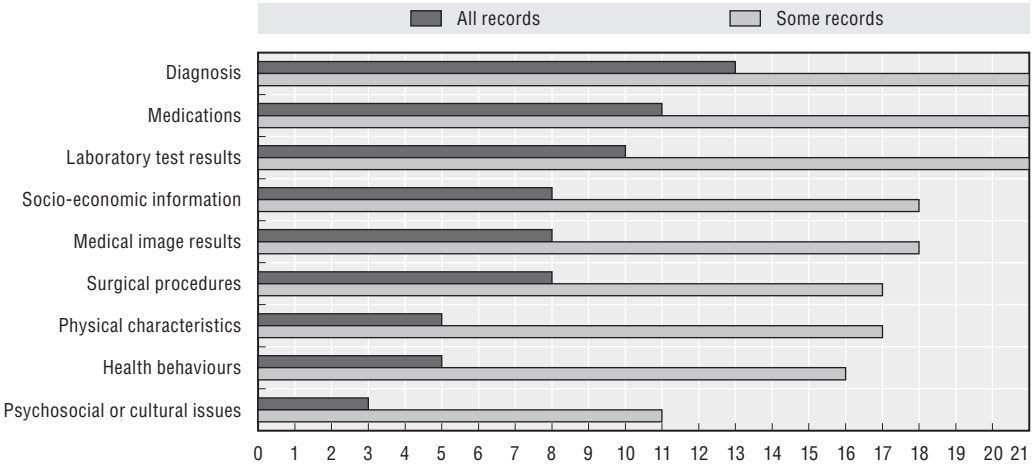
In this study, less than half of countries participating have succeeded in implementing a system where all electronic health records have key data elements that are structured and follow a clinical terminology standard, such as diagnosis, medications and laboratory tests. Most countries, however, report that at least some of their electronic records have reached this level. Less common is the use of terminology standards for medical imaging results, surgical procedures and patient characteristics, behaviours and psychosocial or cultural needs.

The use of structured data that follows a common terminology standard enables data to be analysed using statistical techniques. Countries with more than one terminology standard in use would need a reference to map data from one standard to another, in order to build databases and conduct analysis. Many countries are contending with the use of multiple standards for the same data element. This is because legacy systems may no longer conform to current national standards or to the recommended version of a national standard. It is expensive for health care providers to upgrade their systems when national standards change and it can also be difficult to persuade vendors of legacy systems to upgrade them, if there are no incentives or penalties in place. Where data is unstructured, and where statistical analysis is desired, the use of human coders or sophisticated technologies would be needed to create structured data.

Thirteen countries indicated that diagnosis information is entered into all electronic health records in a structured manner using a terminology standard; eleven indicated the same for medications information; and ten for laboratory test results (Figure 4.1, Table D.16). The number rises to 21 countries reporting structured data for diagnosis, medications and laboratory test results, when countries who reported some or most records will have elements entered in a structured format are also considered.

Less frequently reported is the use of structured data for other types of information in electronic health records. Eight countries reported that all electronic health records will have structured data for medical image results, surgical procedures and socio-economic information. Five countries indicated that all records have structured elements for physical characteristics, such as body mass, and health behaviours, such as smoking and alcohol

Figure 4.1. **Number of countries reporting elements are structured using clinical terminology standards**



Source: OECD HCQI Questionnaire on Secondary Use of Health Data: Electronic Health Records, 2012.

StatLink http://dx.doi.org/10.1787/888932796625

use. Three countries reported all records to have structured data for psychosocial or cultural issues.

In *France*, all elements of the electronic health record are structured; however, free text can be added by the patient in a box called "patient's personal expression". This enables patients to contribute content to their records. France has not experienced barriers to the introduction of one set of national terminology standards. *Estonia* also reports that structured data is used for virtually all of the data elements investigated here. It took time to get all standards to be used and, further, it is resource consuming to ensure that the standards used are kept up-to-date.

All elements of the electronic health record in *Slovakia* are structured elements, with the exception of some unstructured entry of socio-economic data. The country-wide deployment of the national electronic health record will resolve existing inconsistencies in terminology standards in current use. Slovakia has experienced some resistance from the medical community to the terminology standards adopted for the national system.

Denmark also relies on structured data elements for key components of its electronic health record, with some records containing unstructured data for socio-economic status, physical characteristics, behaviours and psychosocial or cultural issues. A recent initiative is the introduction of a common electronic medications list. This list has been implemented in three regions in Denmark and will be used in all regions by the end of 2012. The common list will be shared between hospitals and primary care and medical specialist physician offices through a National Common Medication Database. In Denmark, there is a distinction between the terminology standards in use in primary and secondary care. The introduction of national terminology standards is challenging because it is costly to change systems using existing classifications and terminology.

Iceland also relies on structured data for key components of its electronic health record. Iceland reported that there is a problem of inconsistency in terminologies across the country. For example, both NCSP and NCSP-IS codes are being used to code surgical procedures. Further, local coding systems for disease symptoms are in use in some settings. *Israel* reports that inconsistencies arise in terminology standards when national standards, such as ICD-9-CM, are modified at the local level. Israel plans to introduce ICD-10 and SNOMED, however, there are barriers to overcome, including the costs to change legacy systems.

Singapore reported a mix of structured and unstructured elements, with medical imaging and surgical procedures entered as free text. There are different electronic medical record systems with different localised content and nomenclature across clusters of hospitals in Singapore. A national consensus is being worked on for a nation-wide implementation of standards in several areas, including laboratory test results and medications.

Indonesia has only structured data elements in electronic health records, with the exception of allowing the capture of clinical notes. Hospitals in Indonesia have adopted HL7 standards however primary health care is using different standards which vary by local area. The use of different standards is a barrier to interoperability.

In *Japan*, the "My Hospital Everywhere" project listed the data elements to be included in electronic health records. The first phase would implement pharmaceutical data, and the second phase, laboratory data and discharge summaries. Image data, such as CT and MRI results, were not recommended for inclusion because of the size of the files. Instead,

reports of findings from these images would be recorded by doctors. The terminology standards that may be adopted by Japan have not yet been set. There is a concern that Japan's current coding system for insurance claims may not be consistent with the content of the electronic health records.

Results reported for *Korea* refer to the standards for electronic health records in public health centres. These standards were developed through the Public Health and Medical Institution Informatisation Project. These standards are not yet used by private sector hospitals and there is no policy to motivate them to adopt these standards, particularly given the risks they would incur in changing from their existing standards. Some networks of health organisations in Korea are sharing clinical information electronically using their own proprietary standards. A pilot project lead by the Seoul National University Bundang Hospital, involves 35 clinics in Seongnam City and Yongin City in the sharing of patient information electronically including diagnosis, laboratory and medical imaging results, and prescription medications. Data transfer and semantic standards are being used including HL7 CDA for data transfer, ICD for diagnostic coding, DICOM for images, specific codes for laboratory tests and medications, and fee codes.

In *Belgium*, there is one set of clinical terminology standards in use for electronic health records. There have been some difficulties in introducing the national standards, including that the SNOMED-CT based on the Belgian CMV is under development and will be incorporated into the EHR semantic requirements once it is completed. Syntactic and contextual interfaces also need to be developed for electronic record systems, in order to increase the adoption of the national terminology standards.

Finland also has one set of standards for electronic health record terminology, with all records having structured diagnosis, laboratory tests and medical images elements, and most records having structured elements for medications and surgical procedures. A difficulty in the introduction of national standards includes addressing concerns of clinicians about the usability of the terminology. It is important for vendors to work toward strategies that enable clinicians to more easily enter structured data.

There are inconsistencies across *Austria* in the terminology standards used for electronic health records. It is a national commitment to address this discrepancy, however, the costs of migrating to new standards is a barrier to change.

Slovenia notes that there are inconsistencies between electronic record systems across the country in the terminology standards used. Providers of software solutions have been using different information models and datasets. Effort is underway at the national level to establish a common set of standards and terminologies. Challenges to progress include insufficient knowledge and financial resources. *Spain* reported that state law to establish a minimum data set was published on September 10, 2010 and has been in force since March 3, 2012. The law concretely defines standards used in clinical reports across the country; however, local implementation still lacks sufficient resources to complete the effort. While there are no terminology standards for surgical procedures within the national EHR, this information is provided through an alternative dataset.

Portugal reports that there are inconsistencies in the clinical terminology standards used across the country and that there are difficulties introducing national terminology standards, including insufficient awareness of the value of standardising terminology and the costs associated with changing existing IT systems.

Poland is still in a phase of analysis in advance of making final decisions on the use of terminology standards. Despite the use of an official terminology for laboratory results that is supported by the Association of Laboratory Medicine, there remain local discrepancies in the terminology used across laboratories in Poland. Regional projects are underway to reach a decision on standards for laboratory results. Poland also notes experiencing pressure from the lobbying efforts of companies advocating the adoption of particular terminologies.

In *Canada*, health care is a provincial and territorial responsibility and the 13 jurisdictions have the flexibility to adopt their own standards. As a result, different versions of standards are being implemented by jurisdiction. This is partly the result of differences in existing legacy hospital and clinical information systems, which may pose barriers to the adoption of new versions of standards. The use of structured data is inconsistent across levels of care and provincial and territorial jurisdictions. There are multiple vendors of electronic medical record systems and hospital information systems in Canada. As a result, structured data for diagnosis is not consistently available, but is more available in the acute care sector. The same inconsistency applies to other data elements as well. In some cases, laboratory test results and medical imaging results may be attached to the record as a PDF document. Some jurisdictions have, however, implemented a local laboratory information system and/or a drug information system that captures structured data. Other barriers to the introduction of national terminology standards in Canada include the complexity of the SNOMED-CT reference sets, encouraging and managing change at the level of health care providers, and the ability of vendors of legacy systems to incorporate terminology standards into their products.

The *United States* reported working to sensitise health care providers to the importance of capturing data in structured fields, such as medications and diagnosis. Anecdotal reports indicate that these key fields are sometimes still entered as free text in some electronic record systems. The United States is also working to ease the use of structured fields for many data elements. Socioeconomic characteristics and clinically relevant psychosocial or cultural issues may be entered by physicians as free text in some electronic record systems. There are multiple vendors of electronic record systems in the United States. The capabilities of the systems vary according to the target end user of the system, with products for clinicians more likely to have structured data elements for medications and laboratory results, while products targeted to public and private payers may not have structure for clinical elements. The federal government has mandated the use of terminology standards in medical records and these are the standards reported here (Table D.17). As a result, there is no inconsistency across regions in the clinical terminology standards used.

There are no semantic requirements for the electronic health record system in *Switzerland*. Information may be contributed in a structured or an unstructured format. Also, the terminology standards used differ across health care providers. The different needs and priorities of users of electronic records would make it difficult to introduce national terminology standards.

In *Sweden*, no terminology standards are being used today on a national level for documentation in the EHR, but the national strategy is to increase the use of standardised terminologies. The aim is to use SNOMED CT as a terminology standard on a national level, but the implementation of SNOMED CT is still under development. In connection with the

Swedish strategy for eHealth, the National Board of Health and Welfare is responsible for the development and management of the national information structure and the interdisciplinary terminology for health and social care, including SNOMED CT. The aim of the Swedish national strategy for eHealth is to ensure efficient information supply in health and social care. The National Board of Health and Welfare will, within the strategy, assume overall national and strategic responsibility for making individually based patient and user information clearer and more easily measurable and accessible. The work involves defining and describing the content of appropriate health and social care documentation. The interdisciplinary terminology includes concepts and terms that have been agreed on a national basis and published in the Board's terminology database, statistical classifications and coding systems that have been agreed on a national and international basis and the Swedish translation of the clinical terminology SNOMED CT. The interdisciplinary terminology provides the tools for information that is created around an individual and his/her health to be described in a uniform and clear manner. The detail and structure of SNOMED CT creates conditions to meet the various activities' requirements of concepts and terms in electronic records. The interdisciplinary terminology also provides the bio psychosocial model contained in the ICF, which is used to describe functioning, disability and health.

In the *United Kingdom*, England has implemented a standard for key elements of the electronic record including medications, diagnosis, laboratory tests, medical images and surgical procedures. There are differences in the use of consistent standards, however, between primary and secondary care in both England and Scotland. There is no business case in Scotland for decision makers to accept a single terminology standard or to change existing systems. There is also no agreement among stakeholders as to which terminology will suit all domains. At present, local READ codes are used in primary care and in some secondary care settings. ICD and OPCS codes are used for in-patients in secondary care settings. SNOMED-CT and ICF are both being considered for future use.

In *Mexico*, electronic records for patients began to be introduced about 15 years ago. At that time there were no regulations to govern the adoption of EHR systems. As a result, health care providers implemented terminology or vocabulary that suited their business requirements, including the adoption of different international standards across providers. A barrier to the introduction of national terminology standards is the training of professionals to use new vocabularies correctly.

Terminology standards in use

There is considerable variety across countries in the terminology standards used for electronic health records. Some countries lean more toward the adoption of international terminology standards, while others rely more on national coding systems (Table D.17). Diagnosis is one element where there seems to be greater harmony across countries, with 19 reporting the use of ICD-10 codes and five reporting SNOMED codes. Thirteen countries are using DIACOM standards for the electronic storage of medical images. There is also some consistency in the use of international standards for laboratory tests and medications, with 13 countries using LOINC codes for laboratory results and twelve using WHO ATC codes for medications.

In addition to mapping to the code sets reported in Table D.17, *Finland* is also using ISO standards for medical aids and for languages and countries; *Mexico* is mapping to the WHO

International Classification of Functioning (ICF); *Belgium* is undertaking projects to harmonise SNOMED CT to WHO and local coding requirements; *Korea* is mapping the Korean Standard Terminology of Medicine (KOSTOM) codes to Unified Medical Language System (UMLS) codes; and *France* is mapping primary care encounter codes to SNOMED vf 3.5 and DRC. *Finland* reports that a national code server is used to provide a large range of codes and to assist with data harmonisation.

Unique identifiers within EHR systems

Unique identifiers are crucial to the development of longitudinal electronic health records, in order to ensure that the data within the record is complete and accurate for patients, as they move among health care providers, health insurers, and regions within their country and over time. They are also important for statistical purposes to identify unique patients and to conduct, where approved, linkages of data across more than one data source. It may also become increasingly important to identify the health care professionals entering data into electronic health records, for purposes of ensuring and validating the completeness and accuracy of the record and for statistics related to quality, efficiency and performance.

Belgium, Estonia, Finland, France, Iceland, Indonesia, Korea, Poland, Singapore, Slovakia, Slovenia, Sweden, Switzerland and the United Kingdom (England) report both a unique national identifying number for patients that will be used to ensure the identity of patients to build their electronic health record; and a unique identifying number for health care professionals entering data into electronic health record systems.

Poland will use the PESEL number, which is granted to citizens at birth and to all legal inhabitants, to establish the unique identity of patients to build electronic health records. Poland also assigns a unique ID number to health care professionals including, physicians, nurses, dentists, laboratory specialists and other regulated medical professionals. This ID will be used to establish the identity of medical professionals entering data into electronic health records. A registry of health care providers provides a unique ID number for health care facilities.

In the *United Kingdom*, a unique identifying number for patients and providers is being used for electronic health records in England. In Scotland there are unique identifying numbers for primary care physicians. There are also unique ID numbers for doctors and nurses in secondary care, but these numbers are not routinely used in electronic patient record systems. In *Sweden*, the use of a unique health care provider ID number within electronic health records is not yet fully developed at the national level.

Denmark, Germany, Israel, Portugal, Spain and Mexico report a unique identifying number of patients within electronic health records, but not yet for health care providers. *Denmark* has an ID number for authorised doctors, nurses and midwives but it is not used in local electronic medical records and is only partly used for some centralised services. Denmark is working on how to implement the general use of this authorising ID in electronic records. *Germany* reports a unique identifying number for patients that may be used for electronic records. There is no ID for health care professionals entering data into electronic records; however there are certificate numbers on health professional's membership cards. *Mexico* has a unique identifying number for patients and will use the national population code to identify health professionals; however the identification of health professionals is not mandatory for electronic health records. In *Israel,* the identification of the health

provider is done within the EMR of the organisation the provider belongs to. There is no data entry within the EHR and therefore no need for a provider ID. In Spain, a national registry for health care professionals is under development. In *Portugal*, there are identifiers for the professional group entering data into the record (doctor, nurse, etc.).

Austria is developing a unique ID for both patients and health professionals. The patient ID will be an amalgamation of a national and local numbers and will be used to create a patient registry. The e-Government plan for Austria also includes a unique ID number for health care providers and a registry of providers will also be created.

The *Netherlands* does not have a unique identifying number for patients, but does have other identifying variables that may be used for research requiring data linkage. There is a unique identifying number for health professionals in the Netherlands which is used for health insurance claims. *Japan* has an identifying number for patients but because it is composed of names and dates of birth it is not able to uniquely identify persons.

There is no national unique patient or health care provider identifying number in *Canada*. Patients have a unique health insurance number within each of the provinces and territories. Health care providers are also uniquely identified within each jurisdiction. Regulatory bodies within each jurisdiction manage the identity numbers. Each jurisdiction is defining their own approach to the use of identifiers within electronic health records.

The *United States* does not have a unique patient identifying number and the expenditure of government resources to develop such a number is prohibited by law. Patient summary records and medical records contain patient identifiers: names, addresses and dates of birth that can be used for confirmation or probabilistic data linkage. Health care provider identifying information is not required for every summary record for exchange. There is a national provider identifier system for providers reimbursed for public health care programs and the same system is available and widely used by private health care insurance and care providers.

Smart cards

Smart cards contain an embedded microprocessor that can assist with secure identification of patients and providers to ensure accurate health records and can enable patients to have secure access to services or records on-line. Some countries may include or consider future inclusion of elements of a patients' minimum data set directly within the card, which can serve to assist patients with emergency care.

Belgium, Estonia, France, Israel (partial implementation), *Spain, Slovenia, Switzerland* and the *United Kingdom* (England) have introduced smart cards for both patients and health professionals. Switzerland notes that 80% of mandatory insured persons already have a smart card. Similarly, in *Spain*, about 80% of patients are now covered by a smart card (citizens' dni-e). The distribution of smart cards to providers in Spain is underway. *Israel's* HMOs have introduced smart cards for patients and health care providers. In the United Kingdom (England), the number of patients with a smart card is still low.

Germany has distributed smart cards to patients and smart cards for health professionals are available. *Portugal* has introduced smart cards for patients in some services and is considering the introduction of smart cards for health professionals. *Finland* and *Sweden* have introduced smart cards for health professionals, but not for patients.

Poland plans to implement an electronic ID for patients and health professionals. *Austria* is also introducing smart cards for patients. The *Canadian* province of British

Columbia will introduce a smartcard for patients in 2012 that will enable patients to securely access their health records on-line. Other Canadian provinces are conducting pilot studies of the introduction of smartcards for patients and providers.

Status and technical challenges of database creation from electronic health records today

Twelve countries are using data from electronic health record systems to build databases that can be used for health care monitoring and research and four are planning to do so in the future (Table D.19). A potential challenge within some countries will be the legal and policy frameworks to build national databases involving a large number of database custodians. While many countries report a small number of data custodians, Belgium, Spain, Sweden, the United Kingdom and the United States report more than 20.

Most countries participating in this study (16 countries) cite legal issues as a barrier to the creation and analysis of databases from electronic health records. These challenges will be explored further in the next chapter.

Fourteen countries are also sufficiently concerned with the quality of data within electronic health records to identify this as a barrier to database creation. Other barriers include lack of financial resources or technically skilled personnel to create databases (nine countries), or to de-identify the data to protect patient's data privacy (seven countries).

The complexity of the development, analysis and de-identification of databases, as well as the complexity of assuring requirements of data privacy protection are correctly addressed, may motivate some jurisdictions to identify one or more third parties to assume complex responsibilities. In this study, only three countries have signalled the use of a third party, separate from government, insurance and practitioners, to take responsibility for the creation of databases from EHR records and to undertake data de-identification. Four countries have identified a third party to approve or decline requests for access to data.

Finland reports extensive information infrastructure of person-level health data in established registries. Finland has begun to extract data from electronic health records to populate these registries beginning with the creation of a primary care registry (AvoHilmo). Challenges to database creation include that the register keeper needs to have a legal status and that resources to develop databases are not always sufficient.

Iceland's Directorate of Health has developed a set of registries that rely on data collected from EHR systems. These include national registries for cancer, births, contacts with primary health care centres, patients, prescription diseases and communicable diseases that are all in the custody of a small number of organisations. In *Iceland*, concerns reported include that data are frequently not coded in a timely manner, there is a lack of internal data quality audits within each health care institution and there are financial barriers to building capacity to de-identify databases from EHR records.

Sweden reports over 100 clinical research databases and quality of care registries that depend upon electronic health records. National health databases, such as the National Patient Register, in Sweden also rely upon some elements within electronic health records. As a result, there are more than 20 custodians of databases created from EHR systems. Sweden has reported concerns with the quality of EHR data that may limit database creation and challenges due to a lack of resources to create databases.

In *Slovenia*, data elements within EMRs (such as chronic disease risk factors) are exported to national health databases. Data elements within the EHR system related to quality of care, such as prevention efforts, are exported to national registries, such as the registries of chronic disease risk factors and cardiovascular disease. Custodians of databases from electronic records include the National Institute of Public Health and clinical organisations for particular databases and registries (i.e. oncology, cardiovascular disease). Challenges to database creation in Slovenia include national level shortages of skills and funding and the lack of structured clinical data.

Korea's Public Health and Medical Institution Informatisation Project involves the creation of databases of laboratory test data, procedures, medications, injections, physical therapy, and causes of diseases. Vaccination history is monitored in co-operation with the Korea Centre for Disease Control and Prevention. National health examination data are shared with the National Health Insurance Corporation. Korea has reported concerns with the quality of EHR data that may limit database creation.

In the *United Kingdom*, there are several databases that have been created from data from electronic health records including, in England, the Secondary Uses Service, the Renal Registry, Cancer Registries and research databases; and in Scotland, the SCI Diabetes Disease Register, GP IT Systems – Quality Outcomes Framework data, GP Practice Team Information (PTI), Primary Care Clinical Information (PCCIU), and other disease registers. More than 20 organisations are in custody of databases developed from electronic health records. Challenges to the development of databases from electronic health records include records that are not sufficiently complete or coded and are, therefore, difficult to analyse. In Scotland, this problem is noted to be gradually reducing with improved coding. There are also concerns with the potential disclosure of confidential information and ensuring that appropriate safeguards are in place.

Portugal reports that a central database with data from electronic records for all cases admitted to public hospitals is currently being used to monitor health care management and health care quality. Electronic records are also populating databases related to prescribing and to other smaller disease-specific registries. Overall there are a small number of custodians of these databases including the Central Administration of the Health System and scientific societies. In Portugal, there are concerns with the quality of data entered into electronic records that limit database development.

Canada reports that a few national chronic disease databases have been created, such as the Canadian Centre for Health Information's Canadian Primary Care Sentinel Surveillance Network (CPCSSN). This database is Canada's first multi-disease electronic record surveillance system which has been created to monitor a set of key chronic diseases. To create this database, data is extracted from primary care physician offices' electronic medical record systems for a subset of providers and their patients. Some provinces and territories have created jurisdictional research data centres where databases may be analysed that have been created from electronic health record systems. At a national level, the Canadian Institute for Health Information creates national databases for monitoring health system performance and patient safety and for research. Data submitted by provinces and territories to develop these database may derive from jurisdictional electronic health record systems.

The National Health Fund in *Poland* has created a large database from electronic records related to reimbursement purposes. This data had been poorly used for statistical

or research purposes, however, two years ago several disease registries, including a cancer registry, we prepared from extractions of sub-sets of this larger database. Co-ordination remains an issue, as the roll out of the national EHR is a large project composed of many local initiatives. There is also the challenge of critical opinions to the creation of databases that are not always based on knowledge or experience.

At a regional level in *Spain*, some authorities are establishing data marts or data repositories from EHR systems to support public health, health system management, evaluation and other uses. Data from EHR systems has had limited use for research, and most research studies have been at a local level. There are more than 20 custodians of databases from EHR systems in Spain involving regional health authorities and local custodians. Spain reports challenges to database creation from electronic health records that include concerns with the quality of data; the use of diversified formats, vocabularies and terminologies; lack of support for standardised terminologies; strong bureaucracies and the lack of written policies to support applicants seeking access to data; and ICT providers who may charge health care providers or researchers for access to data for secondary uses.

France is not yet building databases from electronic health records, but intends to do so as this is part of the final phase of the national EHR strategy. There is currently a collaboration project of the National Institute for Cancer and ASIP Santé to build a database of shared oncology records. There will be only one data custodian to develop the databases. French law protects the privacy and security of personal health data and limits analysis of electronic health records to research purposes. *Estonia* is currently implementing database creation and is regularly using data from the national electronic health record system for public health monitoring. *Slovakia* is also planning to build databases from electronic health records in future.

In the *United States*, various providers and professional organisations have implemented clinical data registries. The extent to which these registries are populated with data extracted from electronic health records is not known. The Office of the National Co-ordinator is working to enable and promote the availability of EHR-based submissions to clinical registries and quality measurement systems that are sponsored or otherwise supported by the government. In terms of the technical feasibility of building databases from electronic health records, standards and applications remain in development that will be needed to implement distributed query. Standards and implementation specifications for the routine production and reporting of both quality measures and clinical data registries are in development. Further, some clinical data elements are captured in ways that may require normalisation to compile records across multiple providers. The United States Office of the National Co-ordinator for Health Information Technology (ONC) is engaged in or sponsoring research to increase the ease of routinely capturing health and clinical data in standard formats and with standard terminologies that could eventually reduce the need for normalisation.

Denmark has established an extensive system of established registries that rely on forms completed by health care providers or extractions from existing health information systems to populate them. Considerable will and financial resources would be needed to move away from the current system to a new approach where extractions from electronic health records would populate key databases. Within *Israel*, data is collected for analysis from hospitals and HMO provider EMR systems and not from the HER system.

Singapore reports that variability in the quality of EHR records across institutions; the policy and guidelines needed for data de-identification; the need to establish data governance; the duty of care of users of electronic health records; the acceptance of users and other privacy-related issues, are all challenges that need to be addressed to build and analyse data from electronic health records. In *Switzerland*, challenges to the development of databases from electronic health records include a lack of structured data in electronic medical and health records and limitations to interoperability.

In *Germany*, personal medical data is only to be used for the purposes for which it was originally collected and electronic health data is collected for medical care. Direct access to electronic health record data for other purposes is restricted and only possible when explicitly allowed by law. An example is data extraction for billing purposes. Certain datasets, however, may be extracted in a controlled way and used for other purposes within the constraints of the Data Protection Act. These constraints are not barriers as they are necessary regulations to protect patient's privacy. For the monitoring of health care quality in Germany, the approach has been to extract data from electronic medical records within individual health care organisations. Such data are anonymised or pseudonymised for approved research projects and the approach has been to have national procedures for the creation and management of pseudonyms. To evaluate the complete care process, data linkage at the level of individual patients may take place for approved projects, with merging based on a common pseudonym.

Estonia also expects challenges to database creation from electronic health records. These include a lack of human resources to create databases and concerns with both the quality and patient coverage of discharge letters within the records (epicrises). *France* reported that it is still too early to determine if there may be resource or data quality barriers to database creation.

Canadian jurisdictions have been focussed on deploying their electronic health record systems and this effort has required a greater need for IT resources that are skilled in the development of databases. As well, potential data users will increasingly need to be skilled in data and analytics. These skill sets are still growing in Canada. Existing investments in legacy systems and the ability of health care providers to incorporate clinical terminology standards continues to be a challenge for all jurisdictions and their EHR vendors. While there are standards for interoperability, these standards are still evolving as they relate to data capture (such as structure, format, terminology and coding). Lack of standardisation will impact on the ability to use electronic health records for large-scale analysis.

There will be challenges in the *Netherlands* to the development of databases from electronic health records. These relate to issues of data privacy and ownership of data. Further, monitoring and research often lacks resources, not only to appoint researchers but also to support the use of the data. Past experience has shown that health care providers, who will be the custodians of the data, do not easily allow access to data for projects conducted by research institutes. A further difficulty is that, until now, the possibility of building databases for research from electronic health records was not taken into account in the development of electronic health records.

Analysis of data from electronic health records for statistical purposes and evaluations of data usability

Many countries (11) have already implemented a process to evaluate the usability of data from electronic health records for statistical purposes and many (13) are already regularly using data extracted from electronic health records for some aspects of national monitoring or research about population health and health care services (Table D.20). Thirteen countries reported regular use of electronic health records for public health monitoring; eleven countries reported use for research; and nine countries reported regular use for patient safety monitoring. Less common was regular use for health system performance monitoring (seven countries); supporting physician treatment decisions (six countries); and facilitating or contributing to clinical trials (four countries).

Finland reported undertaking continuous work to evaluate the usability of data from electronic health records. This work is necessary because the structure of the records and of the registries is being standardised. Finland conducts analysis of electronic health records on a regular basis in order to conduct infectious disease surveillance, monitoring patient safety, and supporting physician treatment decisions by enabling physicians to query data. Finland is working toward the use of electronic health records from primary care to monitor the performance of the primary care system. For secondary care, existing registers are used for this purpose. Research to improve patient care, health system efficiency or population health care is conducted in Finland typically only on a local or regional level from electronic health records. At a national level, existing registries are analysed for these purposes.

Slovenia is currently using data from electronic health records for public health monitoring, such as monitoring the number of patients with chronic diseases and risk factors for patients with certain chronic disease types; and for health system performance monitoring, such as tracking office visits of patients with certain chronic diseases and monitoring overall usage of primary, secondary and tertiary care. Electronic records have also been used in Slovenia to monitor patient safety and to conduct research, however, not on a regular basis.

Electronic health records are regularly used in *Sweden* for secondary analysis across all of the dimensions explored here (see Table D.20). National clinical databases of patient problems, medical interventions, and outcomes after treatment; and the National Patient Register of hospital in-patient and outpatient care, form the backbone of Sweden's national monitoring and research infrastructure from electronic health records.

In *Poland*, there is already experience in the development of disease registries from electronic medical records including databases for acute cardiac episodes, haemophilia patients and cancer screening, as well as pilot testing of drug utilisation reports and some published research and data quality evaluation. In Poland, a research project has compared the quality of data from electronic health records with data from the services reimbursement system for the building of a cancer registry. This research has explored the quality of the data to study treatment patterns and outcome measures for cancer care.

The *United Kingdom* is evaluating the usability of data from electronic health records for analytical purposes in both England and Scotland. England, for example, is looking at the ability to re-use SNOMED coding for analytical purposes. England reports capturing central summaries of patient encounters from primary care physician offices as part of an initiative to monitor primary care quality and patient outcomes (Quality and Outcomes

Framework). These summary care records are available for all of England to authorised users. Scotland reports extracting data from the Scottish Care Information system to populate a diabetes reporting system for Scotland. Scotland reports extracting data on hospital in-patients to contribute diagnosis and treatment information to a morbidity database for Scotland. Data from electronic health records currently contribute to public health monitoring in the United Kingdom, including the generation of reports on a practice by practice basis. Electronic records from the reimbursement system in England and from the General Practice system in Scotland are used to monitor health system performance. Data from electronic health records is also used to support physician treatment decisions, such as a cardiac clinical audit in England, and to contribute to research projects involving clinical trials. Other types of research projects with electronic health records may also be approved, including data linkage to undertake risk stratification.

Belgium reported intending to establish a process to evaluate the usability of electronic health records but not until the semantic interoperability layer has been largely deployed. Public health monitoring and monitoring of patient safety are not yet included in the national plan for the EHR, however, it is part of the functionalities of the EHR that have currently been certified. The semantic interoperability layer will need to be first deployed before wide adoption of the use of EHR data for public health monitoring. While Belgium monitors health system performance and conducts research to improve patient care, health system efficiency and population health, data originate mainly from social security records and sentinel sites rather than from electronic health records. Electronic health records are used to support physician treatment decisions by enabling queries to look at groups of patients; such studies are limited to specific use cases, for example, a study of nephrology. EHR records may also be used in future to facilitate and contribute to clinical trials, but such uses will not be possible before the semantic interoperability layer is deployed.

The *United States* is developing, at a national level, methods and mechanisms to collect data from electronic health records for the purposes of quality measurement, patient safety monitoring, surveillance and public health purposes. These methods and mechanisms are in development and are not yet in nationwide use. As part of these methods and mechanisms, data validation and other quality assurances will be undertaken to ensure that the quality of the data is sufficient to support the purposes for which it is being collected and analysed. Methods and mechanisms for supporting physician treatment decisions, by enabling them to query data to examine care and outcomes for similar patient groups, have been implemented in some provider systems in the United States. The methods, mechanisms and governance structures needed to implement this as a national norm have not yet been established. Infrastructure, methods and mechanisms to support the use of data from electronic health records for population health and health services research have not been established at the national level.

At the national level in *Canada*, no data from electronic health records is being used on a regular basis for secondary analysis. However, there is a Primary Health Care Voluntary Reporting System at the Canadian Institute for Health Information where physicians may volunteer to submit data from electronic medical records which is analysed and reported back with key indicators. A supporting electronic tool also allows physicians to query their own data and drill down to understand trends. The Canadian Institute for Health Information also develops and maintains national databases of patient records from existing information systems that are used to report on many aspects of health and health

care. As previously noted, jurisdictions within Canada may further develop the secondary uses of data from electronic heath records. Some have implemented public health care quality reporting.

In *Portugal*, electronic health records contribute, in a limited way, to public health monitoring and to health system performance monitoring through analysis of the hospital in-patient and prescribing components of the electronic health record system. There is also progressively greater use of electronic records from primary care for these purposes. Quality of care indicators are also developed from electronic records. These data sources have also been used for research projects.

In *Singapore*, the evaluation of the usability of data from electronic health records for the development of databases and data analysis is part of the national EHR project; this includes key patient indicators (KPI) and metrics. *Switzerland* has established a process for the evaluation of the usability of electronic health records to contribute to cancer registration, but has not explored other usability dimensions. *Slovakia* and *Estonia* have included in their plans for their national EHR systems to both evaluate the usability of data to develop databases and have planned to conduct secondary analysis of data from electronic health records. *Iceland* reported progress toward the creation of a national patient data warehouse from EHRs where data quality evaluation processes will be included. Iceland is currently regularly using data from its EHR to build registries, as previously noted, and to monitor communicable diseases.

Korea reported that the Public Health and Medical Institution Informatisation Project established the process for the evaluation of the usability of the electronic health record data to develop and analyse databases. Although vendors of EHR systems offer tools for database development and analysis, there are governmental controls as all analysis of EHR data from the project is performed by two authorities, the Korea Health and Welfare Information Service and the Ministry of Public Administration. The Security and National Information Society Agency also manages and controls personal information security.

Currently, EHR data is used in *Indonesia* to develop national health profiles and for research. *Indonesia* notes that the process for procurement for EHR systems is used to require evaluation of the usability of data from the EHR system for the development and analysis of databases. *Japan* notes that national claims databases may be approved for use for public health monitoring and for research currently.