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JASEHN
Joint Action to Support the eHealth Network

REPORT

on

Overview of OECD studies on eHealth and core outcome

Providing the first work on international activities outside EU

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LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

ACRONYM	DEFINITION
APHII	THE OECD HCQI ADVISORY PANEL OF EXPERTS ON HEALTH INFORMATION INFRASTRUCTURE
ATLAS.TI	QUALITATIVE DATA ANALYSIS & RESEARCH SOFTWARE
BIAC	THE OECD BUSINESS AND INDUSTRY ADVISORY COMMITTEE
CITL	CENTER FOR INFORMATION TECHNOLOGY LEADERSHIP
DSS	DECISION SUPPORT SYSTEM
eHN	E-HEALTH NETWORK: A DEDICATED MECHANISM FOR EHEALTH AT THE EU LEVEL IN ORDER TO ENSURE PROGRESS AND BRIDGE THE GAPS BETWEEN THE LEVELS OF GOVERNANCE, STRATEGY AND OPERATION
EHR	ELECTRONIC HEALTH RECORD
EPR	ELECTRONIC PATIENT RECORD
EU	EUROPEAN UNION
G8	GROUP OF EIGHT, A GOVERNMENTAL POLITICAL FORUM OF THE LEADING INDUSTRIAL COUNTRIES
HCQI	THE OECD e-Health expert group
HIE	HEALTH INFORMATION EXCHANGE
ICCP	THE OECD COMMITTEE FOR INFORMATION, COMPUTER AND COMMUNICATIONS POLICY
ICT	INFORMATION AND COMMUNICATION TECHNOLOGIES
JAseHN	JOINT ACTION TO SUPPORT E-HEALTH NETWORK
MAeHC	THE MASSACHUSETTS E-HEALTH COLLABORATIVE
MS	MEMBER STATE (EU)
MWP	MULTIANNUAL WORK PLAN OF THE EHN
OECD	ORGANISATION FOR ECONOMIC CO-OPERATION AND DEVELOPMENT
ONC	OFFICE OF THE NATIONAL COORDINATOR FOR HEALTH INFORMATION TECHNOLOGY IN THE USA
PACS	PICTURE ARCHIVING AND COMMUNICATION SYSTEMS
SPDE	THE OECD WORKING PARTY ON SECURITY AND PRIVACY IN A DIGITAL ECONOMY
UPI	UNIQUE PATIENT IDENTIFIER
VCUR	VENDOR CONFORMANCE USABILITY REQUIREMENTS
WHO	WORLD HEALTH ORGANISATION
WP	WORK PACKAGE

TABLE OF CONTENTS

1. Foreword

The WP8 will work on the 4th axis of the MWP adopted by the eHN, namely "Global cooperation and positioning". The intention is to be able to have an overall vision about what has happened and is planned at the international level, regarding the topics included in the eHN priorities.

The task T8.2 will focus on the international collaboration in specifications and standards and the task 8.1 will focus more widely on the overall vision, policy and initiatives in global eHealth collaboration. One important first step for task 8.1 is to be able to know more about the international organizations such as OECD and WHO; to understand their policies, their working method as well as the way by which they work with the diverse countries and stakeholders.

In order to be able to provide to the eHN an information paper on the main global eHealth activities outside the EU, the tasks members have decided to begin with one international organization most of the member states have already concrete initiatives or actions with. This is the reason why D8.1. will first focus on OECD. As Finland was and is particularly involved and active in some of the OECD initiatives regarding eHealth, Finland was proposed to be the task leader and will propose the first document D8.1.1. It is the first version of an overview of OECD studies on eHealth and core outcome.

Building on the first analysis, we will propose a way of working for the eHN to discuss on and give the WP8 their view on the next steps in order to liaise more closely with OECD if, and when, needed and to avoid gaps and duplication of work on common subjects and objectives.

2. Introduction

The overall ambition from MS is to better include eHealth into health policy and better align Health investments to health needs. A central aspect is the transferability of health data across borders of MS and therefore the organizational, technical, semantic and legal interoperability of eHealth. To create an interoperable eHealth space for Europe means also global positioning of invested interest of MS. This global positioning and cooperation is more successful when done jointly by MS. eHealth is a topic addressed worldwide. The cooperation at EU level should ensure the alignment with ongoing developments outside the EU, so that the agreements made within the eHN are compatible with global developments and standards. The MS are frequently members also in different global organisations where policy decisions on different issues concerning eHealth are made. It is important to the policy makers to assure that the policy decisions made by the countries in different fields are aligned. For this purpose, studies and research done on eHealth developments by the OECD are reviewed.

The aim of D 8.1.1 was to understand the OECD policies, working methods as well as ways of collaboration with the diverse countries and stakeholders specifically regarding the eHN MWP (2015-2018) priorities. The main outcomes expected were 1) a synthesis from the lessons learned - overlaps, gaps, suggestions of what is done outside the EU, 2) a suggestion on how to liaise/align/organize a more close cooperation between the eHN and the OECD with some questions and next step(s) / recommendation(s) for the eHN members to look at/react on and give their feedback and "go-no go".

The first focus for the task 8.1 will be on the overall vision, policy and initiatives of the OECD One important first step for task 8.1 is to be able to know more about the international organizations such as OECD; to understand their policies, their working methods as well as the way by which they work with the diverse countries and stakeholders. Analysis of what OECD wants to do, how and why will be reflected against JAseHN objectives.

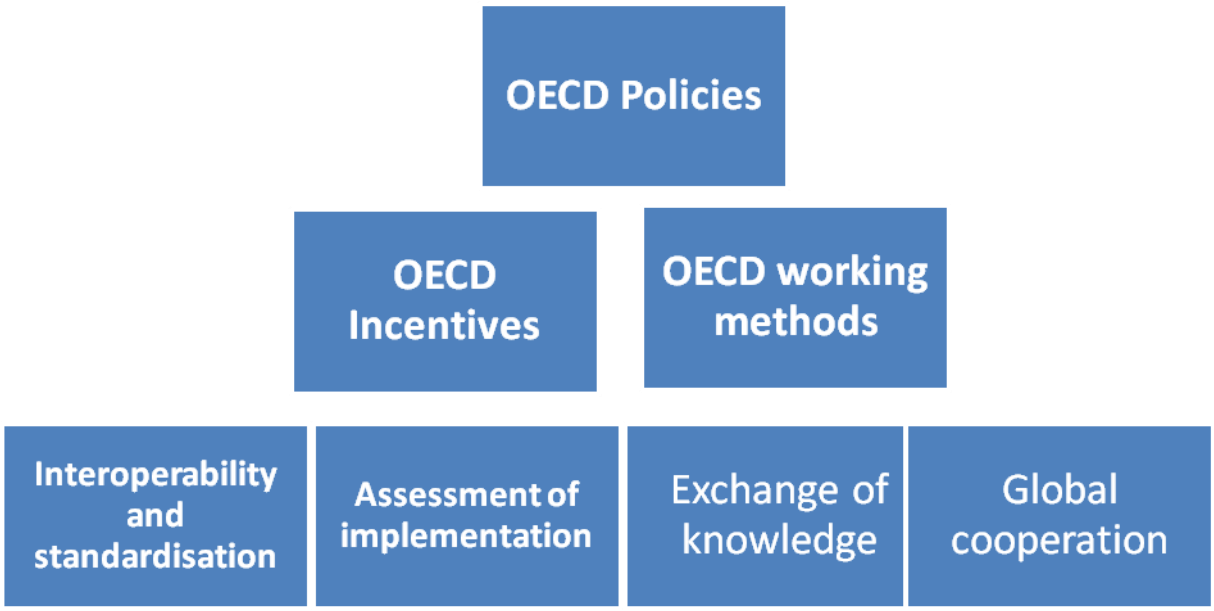

Figure 1: OECD Policies, incentives and working methods

The main objectives of this report are

- To collect information on what the OECD has done on eHealth specifically regarding the eHN MWP (2015-2018) priorities
- To propose a synthesis from the lessons learned. The information is aimed to be useful for the discussions on eHN priorities (overlaps, gaps, suggestions of what is done outside the EU and could be applicable to us)
- To suggest how to liaise/align/organize a more close cooperation between the eHN and the OECD

• To structure some questions and, if possible, at this stage next step(s) / recommendation(s) for the eHN members to look at/react on and give their feedback and "go-no go".

3.1 Methods

OECD policies and studies were analysed by working on OECD publications on eHealth issues during the years 2010 – 2015. The study included also some older publications. The studies and references used as data for this report were searched using a three step-method

1. For version 0.1 of the report, generic OECD website search was conducted using eHealth as the search term. The search provided 540 results, which were reviewed on heading and abstract level. The relevant results were grouped into three groups: a) directly eHealth-related studies and activities, b) Health and cross-border health-related documents and activities, and c) eGovernment and ICT infrastructure-related documents and activities. The search result can be viewed at http://www.oecd.org/general/searchresults/?q=eHealth&cx=012432601748511391518:xzeadub0b0a&cof=FORID:11&ie=UTF-8. This search did not reveal unpublished documents that were known by participation to the OECD work. Results of a Google search (OECD and eHealth) were added to the list.
2. For version 0.2 of the report, and after discussion with the WP8 participants, it was agreed that I) D8.1.1 should focus on selected OECD studies, not on all different OECD activities related to eHealth II) the D8.1.1 should focus mainly on group the "directly eHealth related studies". After this decision, the reference list generated in phase 1 was cleaned, deleting other references than studies. The OECD library was then searched with a simple search of "eHealth" and an advanced search combining "Health" and "information technology". The search result was analysed, and individual studies were added, which were not already listed in the reference list after the first search round. Since many of the studies were in step 1 grouped under groups b and c, but clearly contained an eHealth-element, they were still left on the list.
3. The list was then shared with other WP members, completed with documents still missing but known by WP 8 members and grouped into two: 1) studies focusing solely on OECD and eHealth and 2) studies with other focus, which include an eHealth content. This report contains manly analysis of group 1 studies.

Analysis of the data was performed by two researchers. A detailed policy-level analysis was done as a manual content analysis of printed reports and electronic publications available in the OECD web liberary by one researcher (PH) by classifying and counting statements regarding the policy objectives and implementation tools. The electronically available studies were taken into a qualitative data analysis programme (AtlasTI) by the other researcher (HH) and classified inductively into the different topics. The references in chapter 6 refer to the quotations-document chapters, which is annexed to the report. Results were grouped in to

five themes: 1) OECD policy goals 2) OECD incentives to reach the goals 3) OECD working methods 4) Results of works related to eHealth 5) Global cooperation.

4. Policy goals

4.1 Data and methods for policy analysis

Chapter 9 "references for policy analysis includes" the publications that have been assessed, with the key information related to the policy goals identified in the reports. Nine publications were analyzed. In one of them, no connections with eHealth issues were identified and this publication was dropped from the list. The content was grouped as following: 1) the policy topic introducers, also by funding when information available, 2) the main background policy, 3) the main ICT policy and 4) the main choices/policy to implement the policy.. The connection of the content to the different JAseHN WP tasks has also been identified.

It has to be noted that the "policies" of the OECD are agreed by the Member countries, who are preliminarily interested in the OECD providing comparative analysis to inform their own decisions. Thus this section depicts policy goals that have been identified as the drivers for the studies, not policies of the OECD as an organisation.

The identification of policy drivers from study publications is not possible without a content analysis of texts parts, where such information may be found. This may be even parts others then the main text itself, such as forewords, acknowledgements, introductions or final words. Some of the publications had also references to policy documents. These text parts of the chosen main publications have been systematically read to identify the policy drivers of each work Policy analysis results

One of the works was introduced by the OECD MS health ministers and one by G8 health ministers. EU had participated in the initiative in four and WHO in two. From other international organizations The Commonwealth Fund has been involved in two and the Nordic Council in one. Different member countries had supported the works also with funds. The USA National Science Foundation and the Office of the National Coordinator for Health Information Technology (ONC) were mentioned and also the Ministry of Health of Spain and the German Federal Health Ministry. One work had been funded by six MS:s.

Several of the works had been organized by including them in to the regular work plans of the OECD committees and done under the supervision of OECD expert groups nominated by MSs. The committees mentioned were The OECD Committee for Information, Computer and Communications Policy (ICCP), OECD Health Committee, The OECD Working Party on Security and Privacy in a Digital Economy (SPDE) and BIAC (Business and Industry Advisory Committee. The expert/advisatory groups mentioned were The OECD eHealth expert group, HCQI expert group and the HCQI Advisory Panel of Experts on Health Information Infrastructure (APHII)

4.2 Results of policy analysis

Behind the work plans of all international organizations are the decisions to provide resources to different tasks, such as studies. The concrete outcomes of these decisions are published reports and seminars. There are policy incentives already behind the decisions to introduce studies. Since the members, in OECD the member states, are the decision making body, the policies reflect the collaborative understanding of the members. All the international organizations have been created for some specific tasks, stated in legal documents, and the "reason for the existence" of an organization is also reflected in decisions taken. Since many countries are, as nations, members of several organizations, the countries themselves may have different policies that they choose to promote via different organizations. This means an international organization is not a "stand alone" player in policy formulation. It is a mixture of the collaborative consensus of all the members and the different incentives and policy drives of different members in the background.

The mission of the Organization for Economic Co-operation and Development (OECD) is to promote policies that will improve the economic and social well-being of people around the world. OECD is a forum where the governments of the member states work together to address the economic, social and environmental challenges of globalization. OECD has 30 members. This includes 20 EU Member States. The Commission of the European Communities takes part in the work of OECD.

The introduction of eHealth policy as a tool to implement the policy of high preforming health care systems is a newcomer in the OECD policies. From the work in the OECD Health project, the publication on promoting high preforming health care systems in 2004 (OECD 2004) didn't note the role of ICT at all, and in the work "Health Technologies and Decision Making" (OECD 2005) the only notes on field of eHealth were on telemedicine as a clinical tool that should be assed.

The detailed policy-level analysis specified the following policy targets: (number of publications out of 8 where mentioned):

A. Health system efficiency, value for money = control/reduction of costs (7/8)
B. High-quality of care (6/8)
C. Improvement of society (1/8)
D. Improving the health status of populations (5/8)
E. Streamlining administration,(2/8) and from AtlasTI analysis performance-based governance
F. Protection of privacy (1/8)
G. Independent living (1/8)
H. Healthy lifestyle (1/8)
I. Improving research (2/8)

The role of ICT or eHealth policy targets were also identified in the detailed policy –level analysis. The following were mentioned:

1) ICT contributing as a tool to quality measurement and quality improvement, better health information systems, effective use of registers

2) Introduction and adoption of ICTs, availability of ICTs, More use of EPR*s
3) Effective use of ICT
4) Supporting the development of national information infrastructures
5) Effective use of health data
6) Smarter health and wellness systems
7) Patient empowerment¨
8) Integrated health and social care
9) Privacy-protective uses of personal health data
10) Data governance

The following OECD implementation policy or tools the implement the policies were identified (in out of eight):

1. Computerisation, incentives in ICT deployment, promoting the use of EHRs, expanded use of ICT, especially EHRs (4)
2. UPI (2)
3. Linkage of databases (4)
4. Information sharing, sharing of data , timely access and sharing of patient data via EPRs (3)
5. Monitor and evaluate the adoption, use and impact of ICT, monitor progress of e-health strategies (2)
6. Benchmarking
7. Change management
8. Assuring privacy (6) and security (2)
9. Interoperability/standards, standardized data (2)
10. Measuring quality (2)
11. Developing local information systems
12. Research (2)
13. Innovation, Health innovations (2)
14. System wide accountability, transparency (2)
15. Participatoriy applications,
16. Information on healthy lifestyles
17. Behaviolar modification
18. Personally controlled health records
19. Personalized medicine
20. Big data
21. ICT to support smarter models of care
22. Data governance framework, data governance (2)
23. Secondary use of data,
24. Accreditation/certification,
25. International collaboration
26. New ways of delivering care, Enable entirely new models of healthcare deliver (2)
27. Effective public health planning
28. Evaluation of healthcare interventions and their quality

5. OECD incentives and methods

The key OECD incentives and methods include supporting performance-based and data governance. Working methods include in-depth investigations, exploitation of Expert groups, pilot projects, provision of guidelines, and provision of tools, literature reviews and case studies:

An example of the OECD working methods is the survey to OECD Health Care Quality Indicators Expert Group. The focus was to study the info infrastructure in the MSs. Information on the development and linkage of health and health care data and the development and use of electronic health record systems was gathered and the results were published as an OECD study. (OECD (2013). This work continued as and in depth study where OECD country level data privacy protection experts were interviewed. The focus was to gather information on data governance mechanisms that enable data linkage, privacy-protective monitoring and research, secondary use of health data. The result from this work were the eight suggested data governance mechanisms(OECD 2015a). These results were presented to the OECD Committees. The outcome from these discussions was the introduction of the OECD work on creating Council Recommendations on the usage of health data.

Another example on the OECD working methods is the expert group work to provide a tool for data collection on eHealth implementation. The focus of this work has been to facilitate cross-country data collection, comparisons and learning on the availability and use of health ICTs. (OECD 2015b). The work started with Expert meetings that were followed by the establishment of a working group. The result of this work was an OECD model survey. The work has continued as a collaboration of different countries that have had a voluntary possibility to pilot the data collection and report on the experiences. The focus has been the lessons learned on implementation of common measures (Zelmer et al 2016).

6. Results of studies related to implementation of policy goals

6.1 Personal health data needed to monitor and improve health care quality and efficiency

Timely and accurate health data spanning the continuum of care linked at patient level and safely shared are an essential tool for improving performance of the health care systems and health outcomes of patients, for supporting re-designing and evaluating new models of health care service delivery and for contributing to the discovery and evaluation of new treatments. (5.1; 7.1.1; 7.1.2)

Improved easiness in using personal health data to monitor health and health care quality is connected with improvements in data quality and data standards; with the use of a consistent patient identifier; with data timeliness; with the population coverage of electronic clinical records; with the population coverage of key datasets; with centralisation of data processing; and in data linkage processes. (7.4.6)

Most if not all of these improvements require health ministry leadership on data governance

6.2 Health ministry leadership on data governance necessary

The OECD has published eight key data governance mechanisms to support strengthening national health information systems and enabling multi-country projects to improve the public's health:

1. The health information system supports the monitoring and improvement of health care quality and system performance, as well as research innovations for better health care and outcomes.
2. The processing and the secondary use of data for public health, research and statistical purposes are permitted, subject to safeguards specified in the legislative framework for data protection.
3. The public are consulted upon and informed about the collection and processing of personal health data.
4. A certification/accreditation process for the processing of health data for research and statistics is implemented.
5. The project approval process is fair and transparent and decision making is supported by an independent, multidisciplinary project review body.
6. Best practices in data de-identification are applied to protect patient data privacy.
7. Best practices in data security and management are applied to reduce re-identification and breach risks.
8. Governance mechanisms are periodically reviewed at an international level to maximise societal benefits and minimise societal risks as new data sources and new technologies are introduced (5.1; OECD 2015)

6.3 EHR implementation ensures population coverage

In the 2013 study, 88% (22/25) of countries reported having a national plan or policy to implement electronic health records and 20 reported starting its implementation (7.1.3)There has been progress from 2011 to 2013 in dataset availability among the twelve countries that participated in the OECD HCQI Information Infrastructure surveys. Highest population coverage is in the key datasets of Denmark, Finland, Sweden and Iceland. (7.4.6)

6.4 Health records data quality needs to be ensured

A widely reported barrier to the use of data from electronic health record systems is concerns with the quality of the data, including both a lack of coded data and poorly coded data (7.5.1)

Health care professionals entering and coding data requires new approaches to ensure that data records are of high quality, such as health care provider training, data usability evaluations and auditing for data quality.(7.2.2)

Very few countries reported auditing the clinical content of electronic records for quality in the 2013 study (7.5.1).

6.5 Possibility to link data still a serious problem

Even with good population coverage, linkages of ICT systems and data collected in silos remain a serious problem. Also, key areas of health care (e.g. primary care, long-term care

and prescription medicines) are often not included in data linkages to monitor quality and health system performance)7.1.5)

Prerequisites for linking data at patient level are that key datasets have sufficient detail to enable valid and reliable dataset linkages (Unique Patient Identifier). (7.1.1, 7.1.5, 7.2.3) and interoperability. Introduction of new technologies, new health data and new data privacy protection risks call for revision of current data de-identification methods (7.1.6)

6.6 Standards for interoperability necessary but not sufficient to ensure data linkages

A conceptual framework describing maturity of information sharing has been developed by the Center for Information Technology Leadership (CITL). Each of the 4 stages in a progressive shift to full interoperability adds value, particularly if high clinical value areas are targeted first (7.2)

Level	Attributes
1	Non-electronic data – no use of ICT to share information. The most commonly used manual process for sharing information is either in writing or orally. Human facilitation is exclusively relied upon to aggregate, review, and abstract data from paper sources. Examples: postal mail, phone
2	Machine transportable data – transmission of non-standard information via basic ICT; information within the document cannot be electronically manipulated. Clinicians can access the information, but no computerised data processing or logic can be applied. Examples: PC- based exchange of scanned documents or manual faxing, pictures, portable document format (PDF)
3	Machine-organisable data – transmission of structured messages containing non-standardised data; requires multiple interfaces that can translate incoming data from the each of the sending organisation's vocabulary to the receiving organisation's vocabulary; usually results in imperfect translations because the vocabularies used have incompatible levels of detail. Data content is indexed down to single fields, however human translation is required to convert actual data in each field from the vocabulary of the sending organisation to that of the receiving organisation. Examples: secure e-mail of free text, or PC-based exchange of files in incompatible/proprietary file formats, HL-7 messages
4	Machine-interpretable data – transmission of structured messages containing standardised and coded data; the ideal situation in which all systems exchange information using the same formats and vocabularies. All systems exchange data using the same messaging, format, and content standards, removing the need for multiple customised interfaces. All content can be extracted and converted electronically in each field and no longer requires human intervention. Examples: automated exchange of coded results from an external lab into a provider's EMR, automated exchange of a patient's "problem list".

Source: Center for Information Technology Leadership; Walker *et al.* (2005).

Table 1: A CITL taxonomy for HC information exchange and interoperability

Success strategies for interoperability depicted in studies include setting national standards for the content of the records with terminology standards and the data is structured to be comparable; and setting interoperability standards, so that each electronic record system deployed in the country can speak to another. (7.2.2).

However, consensus is missing on which standards should be implemented, and how, leading to inconsistent medical terminology, clinical records and data storage, creating a barrier to seamless exchange of information. This coupled with rapidly evolving technological solutions, leads to high risks of failure and poor returns: "*Progress toward internationally comparable indicators of health and health care from electronic clinical data will require greater harmonisation toward internationally-agreed terminology standards. (1:324)* Additional mechanisms to promote consistent implementation of standards include appropriate incentives, consensus building and other enabling policies: detailed negotiations between the vendors, overarching leadership enabling successful EHR deployment in physician practices, certification of health ICT products and financial incentives for the adoption of certified health ICT systems. (7.2.2)

Even certification of ICT products does not ensure interoperability, it can only ensure a baseline of core functionalities and specifications that could be used to achieve interoperability. A few countries have therefore chosen to target the vendor with a number of "usability" requirements such as service levels, technical support responsiveness, financial viability, etc (VCUR) (7.2.5)

OECD findings suggest that business cases for the ICT initiatives need to be clearly defined. The long-term sustainability and financing issues appear to be the most challenging and, in most cases, unknown aspects of the ICT initiatives reviewed in studies (5.3)

In case studies, Governments also occupied a central position as initiator, funding provider, project facilitator, and neutral convener (5.7) Persuasive measures include support measures such as providing education and training for change management). (5.6)

Even if these initiatives appear very promising, there is still limited evidence that they have significantly improved interoperability (5.5)

6.7 Managing safe use of health data requires regulation on privacy and security

Managing the safe use of health data is according to study (1) a major concern across the OECD, having direct impact on sharing of personal health data, and even causing patients to engage in "privacy protective behaviours" (avoiding screening tests, treatment, or taking part in research protocols). The development and publication of policies or guidelines greatly increases public transparency. (7.1.6; 7.2.2)

The case studies clearly indicate that appropriate privacy protection must be incorporated into the design of new health ICT systems and policies from the outset, because it is often difficult or impossible to introduce effective privacy protections retroactively, undermining public trust, which is hard to restore. (7.4, 7.2.1)

The 1980 publication of the OECD privacy guidelines are recognised as representing *"the international consensus on privacy standards and providing guidance on the collection of personal information in any medium",* subsequently reflected also in the 1995 Data Protection Directive of the European Union (95-46-EC).

Challenges found in studies related to privacy regulation include 1) ensuring that health authorities and health care providers abide by the regulation 2) harmonising and ensuring consistency of regulation related to personal health data (both nationally and locally), 3) Patient consent (identified as one of the main "road blocks") 4) lack of obligation for care providers to contribute to provision of data for statistical purpose 5) constraints to extracting data from EHRs for secondary purposes (7.2.2; 7.2.3)

6.8 Monitoring implementation of e-health strategies needed, programmes scarce, data not comparable

Developing and implementing national e-health strategies calls for monitoring progress to ensure that efforts made are effective. Without this information it is not possible to evaluate the outcomes of the policies and identify practices from which countries could learn. (7.4.1)

Study 4 highlights an absence of independent, robust monitoring and evaluation of programmes and projects to determine the actual payoff from the adoption and use of ICTs. Available national and international data on health ICTs are rarely comparable, making it difficult to draw conclusions on ICT adoption, use, or impact on care within and across countries, or to evaluate progress and outcomes of their policies and identify practices from which they could learn. (7.4)

OECD produced a model survey to support national measures of the availability and use of health ICTs that can be compared to those of other countries. The development was guided by three overarching principles. First, measures needed to respond to policy and information needs of countries along a continuum, starting from ICT availability, moving towards effective use, and ending with measuring outcomes and impact on population health. Second, the OECD "model survey" framework was used, composing the survey of separate, self-contained modules. The third principle was to use a functionality-based approach to defining key types of health ICTs.(7.5.2)

Piloting model OECD model survey in national data collections showed substantial diversity in health ICT availability and use in all domains. The project also identified methodological considerations (e.g., structural and health systems issues that can affect measurement) important for future comparisons. There were some discrepancies in data collected by the EU and by national sources. By identifying variations and describing key contextual factors, benchmarking offers the potential to facilitate cross-national learning and accelerate the progress of individual countries. (Zelmer et al 2016) 7.4.1

The ultimate strategic objective of implementation of ICTs is to improve the efficiency and quality of clinical care through health ICTs (7.5.2) OECD Health Care Quality Indicators Programme has been developing and reporting indicators of quality and performance for 10 years, resulting in progress in the methodologies for comparable indicators, as well as in the development of the underlying data that enable the indicators. According to the OECD study published in 2013, only 50% of OECD countries were able to report quality indicators requiring dataset linkages, such as mortality within 30 days after hospital admission for AMI or for Ischemic stroke (OECD, 2013b). There are collaborative efforts funded by the

European Union to advance health system performance and quality through analysis of large-scale databases, such as the EU seventh framework research programme EU-ADR, EuroHOPE, and ECHO (7.4.6)

To date, there is paucity of programmes for linking the Health Care Quality Indicator data with data on availability and use of Health ICTs to study Health ICTs as predictors of Health care Quality.

6.9 Open government health data

Initiatives to promote open government health data support transparency to the public and use of data for policy making, administration, consumer knowledge, business innovation, and so on. The United Kingdom shares an important lesson-learned about the necessity of public consultation and communications that must accompany national plans and efforts to develop data governance that maximises societal benefits and minimises societal risks. 7.1.7

Some countries have concentrated the collection and processing of key national personal health datasets. In countries where there is a widely used and accurately captured unique patient identifying number, data linkage services can be a routinized and automated process requiring few resources. 7.1.8

6.10 Results on cost-benefits

Existing evidence is not sufficient to clearly define who pays for and who benefits from health information technology implementation. Case studies show that Health ICTs can 1) increase the safety of medical care 2) improve workflows by facilitating tasks such as medication reconciliation, and by bringing DSS to the point of care 3) reduce operating costs of clinical services 4) reduce administrative costs 5) achieve "transformation" of care by effectively providing means to implement changes that are otherwise impossible, improving access to care (telemedicine), improving cronic care, multiple service delivery and care coordination, and improving feedback on quality of care. The MAeHC has developed standardised and nationally-recognised metrics using data directly from HIEs that can be used to monitor quality and cost of care, providing a shorter feedback loop for clinicians who can adjust their working practice as appropriate (7.5.3)

Specific components or functionalities of EHRs (e.g. ePrescription) are likely to have more positive effects on efficiency than others and depending on context. The use of ICTs to increase compliance with guideline-based care, particularly for chronic diseases associated with preventable hospitalisations, provides an opportunity for significant savings. (PACS) are considered to improve the processing time (or overall "throughput") of medical images and a cost-effective electronic alternative to conventional methods of storing images (7.5.3)

Administrative processes such as billing represent a prime opportunity for savings. (7.5.4)

6.11 Studies organisational change

Case studies show that ICTs can achieve "transformation" of care by providing means to implement changes that are otherwise impossible, e.g. by improving access to care (telemedicine), by improving cronic care (e.g. by enhancing conformity to care guidelines), by

improving multiple service delivery and care coordination, and by improving feedback on quality of care for clinicians who can adjust their working practice as appropriate (7.5.5)

6.12 Results on data exchange

Study 1 depicted OECD guidelines for protection of privacy and the transborder flow of personal data (7.3) The studies remind that legislative frameworks are directly linked to ability of sharing identifiable national personal health data among data custodians or government entities and approving personal health data, after de-identification, for access by applicants from different sectors of society and by foreign applicants (6.12)

A new initiative supporting multi-country data sharing is presented in study 4 – the Farr Institute in United Kingdom (7.3)

7. Global cooperation and knowledge exchange

Concrete collaboration has focused especially in development of eHealth benchmarking, developing indicators and conducting research on health care system performance, and Health data protection (8.6, 8.7, 8.8)

Study (1) reveals several areas where continued international collaboration is essential for monitoring and sharing best practices and lessons learned in development of health information infrastructure and data governance: developing the norms necessary for governments to certify or accredit data processors; develop guidance for the implementation of project approval bodies; ensure that there are sufficient agreed international standards for data coding and interoperability; support countries to evaluate which national legal frameworks for the protection of health information privacy provide adequate protections to facilitate multi-country statistical and research projects; review current practices in patient consent and in waivers to consent to reach a common understanding about mechanisms that are privacy protective; review developments in data security risks and threats and mechanisms to address them explore mechanisms to engage the public in discussion about data and its governance to ensure that there is good public awareness of health data, the benefits of its use, its protection, and the rights of data subjects

Further step will be developing a risk classification of data and data uses that will enable even very sensitive data to be used for research and monitoring (8.5)

WHO was mentioned in the studies in five different contexts: As source for coding systems, As source of term definitions: As source of glossaries in the studies to set survey questions in context: As a member of Expert groups: As setter of policy goals (8.1)

Commonwealth fund was mentioned in the studies in the following contexts: As reference: As co-financer of developing the ICT benchmarking tool: As conductor of ICT surveys: (8.2)

European Union was mentioned in the studies in the following roles: As a funder of efforts to advance health system performance and quality through analysis of large-scale databases; As a participant in projects: As a reference to results of projects supporting policy priorities; As implementer of OECD guidelines: As participant in the OECD work (8.3)

HIMSS collaboration focused on two areas: As a source for data on country-specific plans or policies to develop national EHR systems: As reference (8.4)

8. Conclusions and discussion

Analysis of the studies made it possible to analyse specific policy goals behind the OECD studies, incentives and methods to reach them and related study results. The synthesis aims at discussing, how eHN can help assist OECD in gaining a Europe-wide perspective, and how OECD can assist eHN in summarising what happens in the rest of the world. At present there seems to be a lot of duplication and a missed opportunity. Summary of the findings and synthesis on gaps, overlaps and lessons learned is presented below.

8.1 Summary of the findings

The OECD member states are the decision making body, thus the policies reflect the collaborative understanding of the members. The mission of the OECD is to promote policies that will improve the economic and social well-being of people around the world. The policies are a mixture of the collaborative consensus of all the members and the different incentives and policy drives of different members in the background. Since OECD is a global organization EC and EU member states are among the bodies that are forming the policies.

The introduction of eHealth policy as a tool to implement the policy of high preforming health care systems is a newcomer in the OECD policies. It has not been discussed much longer than 10 years. The most important policy targets are health care system efficiency "value for money" and high quality of care as an outcome from value for money. Improving the health status of population is also mentioned and some focus is on topics such as independent living, research and privacy. The variety of health care ICT specific policy targets is more scattered. ICT as a contributor of tools for measurement and quality improvement is the strongest. Promoting the use of EHR.s and other ICT is a policy priority also. Data governance and assuring privacy are strongly focusing on the secondary use issues. Innovative "smarter systems", patient empowerment and integrated care are also found in some policy statements.

A part of a policy is the choice of implementation mechanisms. A long list of different ways to implement the policies was identified. Most mentionings were on assuring privacy and different aspects of computerization. Ability to do linkage of databases and patient information sharing via EPR:s had also several mentionings. Suggesting the implementation of a policy by doing the following issues was found more than once in the documents for UPIs, monitoring eHealth strategies, interoperability, measuring quality, research, innovation, system accountability, data governance and new care models. The full list is in chapter 4.1.

The key OECD incentives and methods include supporting performance-based and data governance. Working methods include in-depth investigations, exploitation of Expert groups,

pilot projects, provision of guidelines, and provision of tools, literature reviews and case studies

Results of the OECD studies related to eHealth show that

- Availability of personal health data is regarded essential for monitoring and improving health care quality and efficiency and performance-based governance
- Health ministry leadership on data governance is regarded necessary for managing data use. The OECD has published 8 data governance principles to support strengthening national health information systems
- Implementation of EHRs needed to ensure population coverage of personal health data
- Health records data quality needs to be ensured, lack of coded data and poorly coded data remain a problem, auditing is rare
- Linkages of ICT systems and current data collected in silos remain a serious problem
- Progressive introduction of interoperability from non-electric data to machine readable data provides a continuum of added value of HIE and interoperability. National standards on ICT and semantic interoperability are needed but not sufficient to ensure data linkages
- Managing safe use of health data requires regulation on privacy and security, which also increases public transparency. The OECD prepared privacy guidelines reflected in the EU data protection directive. Design of new health ICT systems and policies need to incorporate privacy protection from the outset, retrospective measures are seldom effective. Further challenges include harmonising and ensuring consistency of regulation related to personal health data (both nationally and locally); ensuring that health authorities and health care providers abide by the regulation; Patient consent (identified as one of the main "road blocks"); lack of obligation for care providers to contribute to provision of data for statistical purpose; constraints to extracting data from EHRs for secondary purposes
- Initiatives to promote open government health data support transparency to the public and use of data for policy making
- OECD has published guidelines for protection of privacy and the transborder flow of personal data. Legislative frameworks are directly linked to ability of sharing identifiable national personal health data across countries and approving de-identified data for access by applicants from different sectors of society and by abroad
- Monitoring implementation of e-health strategies is needed, but evaluation programmes are scarce. OECD model survey harmonises indicators on availability and use of key ICT-functionalities and information. Piloting of the model survey variables by implementing them into the national surveys showed important lessons on methodology as well as substantial diversity in health ICT availability and use in all domains measured.
- Existing evidence is not sufficient to clearly define who pays for and who benefits from health information technology implementation. Case studies show that Health ICTs can 1) increase the safety of medical care 2) improve workflows by facilitating administrative and clinical tasks such as medication reconciliation, and by bringing DSS to the point of care 3) reduce operating costs of clinical services 4) reduce administrative costs 5) achieve "transformation" of care by providing means to implement changes that are otherwise

impossible, by improving access to care (telemedicine), by improving cronic care, multiple service delivery and care coordination, and by improving feedback on quality of care for clinicians who can adjust their working practice as appropriate

- OECD has worked for over 10 years to develop indicators for monitoring health care quality and efficiency. To date, there is paucity of programmes for linking the Health Care Quality Indicator data with data on ICT interventions to study Health ICTs as predictors of Health care Quality.

Global cooperation has focused on development of eHealth benchmarking, indicators for and research on health care system performance and Health data protection. Continued international collaboration is essential for monitoring and sharing best practices and lessons learned in development of health information infrastructure and data governance to 1) develop the norms necessary for governments to certify or accredit data processors; 2) develop guidance for the implementation of project approval bodies (of data for sec. purp; 3) ensure that there are sufficient agreed international standards for data coding and interoperability; 4) support countries to evaluate which national legal frameworks for the protection of health information privacy and provide adequate protections to facilitate multi-country statistical and research projects; 5) review current practices in patient consent and in waivers to consent to reach a common understanding about mechanisms that are privacy protective; 6) review developments in data security risks and threats and mechanisms to address them 7) explore mechanisms to engage the public in discussion about data and its governance to ensure that there is good public awareness of health data, the benefits of its use, its protection, and the rights of data subjects

8.2 A synthesis useful for the eHN priorities, overlaps and gaps

OECD policies vs EU policies

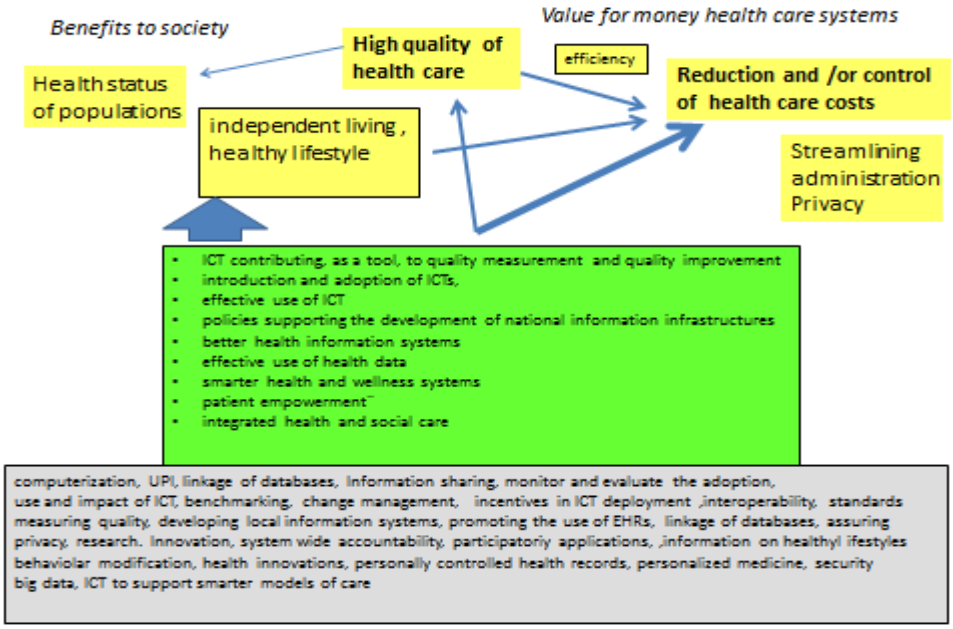

Figure 2: Synthesis of OECD policies on eHealth and their implementation

The main focus of the policies behind the OECD studies is health care efficiency, value for money; savings or getting the best quality with available resources. The means to promote this include good health information systems with a possibility to measure quality. Different ICT solutions in health care are also seen as tools for cost effective services. ICT tools for independent living and health promotion are seen as tools for reducing the need for care and care costs. Social well-being of people; in the health care sector population health is less emphasised in the OECD documents as a driver for policy.

The vision of the EU eHealth Action Plan 2012-2020 differs from the OECD priorities that were found in the documents. The policy focus of the EU eHealth Action plan is on improving chronic disease management and to strengthening effective prevention and health promotion practices, increasing sustainability and efficiency of health systems by unlocking innovation, enhancing patient/citizen-centric care and citizen empowerment and encouraging organisational changes to foster cross-border healthcare, health security, solidarity, universality and equity and to to improve legal and market conditions for developing eHealth products and services.

8.2.1 Synthesis on interoperability and standardisation

OECD has identified interoperability and standardisation as a tool to build better information systems, mainly for eHealth system performance monitoring and improvement. This differs from the focus of EU, where the eHealth interoperability framework is already in its implementation phase. The OECD studies showed that there are different mechanisms to improve interoperability, but they have still not managed to solve all challenges related to interoperability.

8.2.2 Synthesis on exchange of knowledge

Exchange of knowledge on eHealth policies or national eHealth strategies has been an important area of knowledge exchange in the EU, but similar activity was not identified from the OECD material

Focus on exchange of knowledge related to secondary use of health data is quite similar in the OECD and EU

8.2.3 Global positioning

The EU is interested in monitoring eHealth policies outside EU, but the OECD material did not support the fact that OECD would have conducted such analysis.

8.2.4 Monitoring, assessment and implementation

Implementation of eHealth guidelines (patient summary and ePrescription), data protection and regulation and legal interoperability are the main focus in the EU, which are monitored by implementation of concrete EU-level projects

The MWP Section on knowledge exchange includes section on research on added value of eHealth tools, but this is restricted to HTA work, not benchmarking ICTs. EU has

conducted eHealth benchmarking as separate studies (hospital and primary care benchmarking twice), but it is not systematically on the multiannual EU working plan agenda. The OECD has ICT benchmarking as one of the issues on their policy agenda, but they focus on tools (model survey) and indicators on benchmarking. The data on commonly agreed OECD eHealth indicators are collected by national bodies as part of countries' own benchmarking.

The OECD developed and piloted a model survey for monitoring benchmarking health ICTs, to be used by the member states. EU is using its own tools for benchmarking health ICTs. The contents of the OECD and EU tools are not identical, whereby comparison is not without problems.

At the moment, there is a gap on OECD measures to monitor some aspects of quality of ICT systems (e.g. no measures for standards used, ICT system reliability, usability and utility for primary and secondary purposes, user satisfaction and quality of information provided) as well as user experiences on utility and impacts on care processes and outcomes. The publications also do not reflect direct connection between the ICT interventions (ICT indicator values) and changes in health care quality indicator values.

8.3 Suggestion how to liaise/align/organize a more close cooperation between the eHN and the OECD

8.3.1 Cooperation in data governance

Secondary use of data and ICT benchmarking are two common areas of interest within the EU and the OECD. The OECD has worked for several years towards OECD council recommendations on secondary use of health data, and EU is beginning implementation of the new privacy regulation.

Suggestion 1. It is extremely important to align the OECD council recommendations and EU privacy regulation.

Promoting open government data (including the eHealth benchmarking (maturity data)) is supporting transparency to the public and use of data for policy making, administration, consumer knowledge and business innovation is also a common goal. EU is discussing eHealth maturity reporting with the Eurostat[1].

Suggestion 2: Demand on systematic statistical reporting of eHealth maturity turns eHealth monitoring and benchmarking results into a part of countries' statistical knowledge-base building. This needs to be recognized in the EU and country-level eHealth policies with relevant resources reserved

[1] Eurostat survey data collection is based on National surveys that follow the Eurostat model survey which ensures a high level of comparability. Compliance with the Eurostat definitions and recommendations is verified through the methodological reports, following a harmonised reporting template defined by Eurostat

8.3.2 Cooperation in interoperability

The EU eHealth action plan calls for identification of more detailed specifications, for example for public procurement, contributing to the technical and semantic levels of the eHealth Interoperability Framework. In the EU, the eHealth interoperability framework is already in its implementation phase. Results on different levels of interoperability in the OECD studies showed that implementation of interoperability at different levels have not necessarily been sufficient to solve the problem.

Suggestion 3. Detailed results of the OECD results on barriers could be used to support implementation of the EU framework, which could provide a useful framework also for the OECD level studies.

8.3.3 Cooperation in exchange of knowledge

The Commission eHealth action plan states that from 2013 the Commission shall promote policy discussions on eHealth at global level to foster interoperability, the use of international standards, develop ICT skills, compare evidence of the effectiveness of eHealth, and promote ecosystems of innovation in eHealth. The OECD studies note a growing consensus that any national EHR strategy should go hand-in-hand with efforts to achieve system-wide secure exchange of health information, if it is to realise the promise of ICTs. This, in turn, crucially depends on compliance with standards and interoperability.

Exchange of knowledge on eHealth policies or national eHealth strategies has been an important area of knowledge exchange in the EU, but similar activity (content analysis of eHealth policies in member states) was not identified from the OECD material

Suggestion 4. OECD could be interested in exchange of knowledge of the national eHealth strategies in the EU countries and could possibly provide more information of eHealth strategies from countries outside EU.

8.3.4 Cooperation in facilitating uptake and deployment of eHealth

It is stated in the eHealth action plan that by the end of 2013, the Commission will prepare the governance for the large scale deployment of interoperable eHealth services under the CEF 2014 – 2020, taking into account the recommendations of the eHealth Network. This section of the action plan refers to HTA for measuring the added value of eHealth. OECD has developed indicators for health care quality and efficiency for 10 years.

Suggestion 5: Testing utility of OECD HC quality indicators as measures of added value of eHealth for those ICT functionalities that are available, adequately used and have relevant impact mechanisms, could be a way towards a more efficient and automated monitoring of eHealth impacts via register data.

8.3.5 Cooperation in global positioning

The EU eHealth action plan section 7 on global collaboration states that from 2013 the Commission shall enhance its work on data collection and benchmarking activities in health

care with relevant national and international bodies to include more specific eHealth indicators and assess the impact and economic value of eHealth implementation.

There is a shared understanding of importance of and emphasis on eHealth benchmarking within the EU and the OECD that forms a good ground for collaboration. Working methods of the OECD and EU differ, but both need harmonious, reliable data on eHealth maturity in the member states. Both OECD and EU also share similar areas of interest in monitoring, including patient empowerment (PHR-variables in the OECD-study), mobile health, telemedicine and ePrescription.

Suggestion 6: Cross-country collaboration is required on a) EU-level eHealth indicator harmonisation, b) collection (increasingly available from logs and registers) of reliable and valid data on eHealth maturity and c) reporting. The OECD methodologies and tools to harmonize eHealth indicators provide reliable and valid data and could be implemented also in the EU

8.4 Closing Remarks

The main emphasis of the analysed studies from the OECD economic organisation is on use of personal health data for secondary purposes (enhancing health care system performance). ICT system quality (e.g. reliability, available functionalities), information availability, service availability, system use, usability and utility for clinical and citizen decision making are not as the main focus, even though they directly impact with care quality and efficiency.

The results of this document are limited to the findings of the listed studies, and interpretation of the two analysts that conducted the study.

9. References

References used for analysis with Qualitative data analysis programme

P1: OECD (2015), Health Data Governance: Privacy, Monitoring and Research, OECD Health Policy Studies, OECD Publishing, Paris. http://dx.doi.org/10.1787/9789264244566-en

P2: OECD (October 2015) Health Data Governance: Privacy, Monitoring and Research - Policy Brief. www.oecd.org/health

P3: OECD (2013), Strengthening Health Information Infrastructure for Health Care Quality Governance: Good Practices, New Opportunities and Data Privacy Protection Challenges, OECD Health Policy Studies, OECD Publishing. http://dx.doi.org/10.1787/9789264193505-en

P4: OECD (2010) Improving Health Sector Efficiency. THE ROLE OF INFORMATION AND COMMUNICATION TECHNOLOGIES. OECD Health Policy Studies, OECD Publishing, www.oecd.org/publishing/corrigenda

P5: OECD (06-Feb-2015) DRAFT OECD GUIDE TO MEASURING ICTs IN THE HEALTH SECTOR. COM/DELSA/DSTI(2013)3/FINAL.

References used for manual policy analysis

STUDY (respective reference in Atlas TI)	Policy /policy topic introducers	Main background policy	role of ICT, eHealth policy	Implementation policy	JAseHN
"Achiving Better Value for Money in Health Care"(2009) (Not electronically available for AtlasTI)	MS of OECD and MS of EU	Health system efficiency, value for money = control/reduction of costs A	contributing, as a tool, to quality measurement and quality improvement	computerization, UPI, linkage of databases	eID, Guidelines on Patient registers, WP5, Secondary use of data WP 7
Improving Health Sector Efficiency *The Role of Information and Communication Technologies 2010 (P4)*	OECD (ms financial support 6 countries, EU DG health and consumers, co-funding) OECD eHealth expert group	High-quality, value-for-money health care system *i.e.* one based on both quality of care and value for money. Efficiency, quality gains AB	Introduction and adoption of ICTs, effective use of ICT	Information sharing monitor and evaluate the adoption, use and impact of ICT benchmarking change management privacy incentives in ICT deployment interoperability/standards	standards WP5
Improving Value in Health Care, Measuring Quality 2010 (Not electronically available for AtlasTI)	HCQI expert group members, Nordic Council, Commonwealth Fund, EU	Improving quality of care, Improving health care systems value of health care, quality of health care systems, improvement of health care matters to economy and society ABC	policies supporting the development of national information infrastructures	measuring quality, standardized data, developing local information systems, promoting the use of EHRs, UPI, linkage of databases, assuring privacy	eID, Guidelines on Patient registers, WP5, Secondary use of data WP 7 standards WP5
Strengthening Health Information infrastructure for Health Care Quality Governance (2013) (P3)	MS Health Ministers[2]	(improve health status of populations) Value for money, high-performing health systems, improving quality of care, reducing medical error, streamlining administration, protection of privacy ABDEF	Better health information systems, effective use of health data, ,	expanded use of ICT, especially EHRs, measuring quality	eID, Guidelines on Patient registers, WP5, Secondary use of data WP 7
ICTs and the Health Sector TOWARDS SMARTER HEALTH AND WELLNESS MODELS. 2013 (Not electronically	OECD Committee for Information, Computer and Communications Policy (ICCP), USA National	improve efficiency and quality of health care independent living , healthy lifestyle better and more efficient care finance	smarter health and wellness systems patient empowerment¨ integrated health	research innovation system wide accountability paricipatoriy applications, information on healthy lifestyles behaviolar modification Health innovations	

[2] OECD(2011), "Meeting of thr Health Committee at the Ministerial Level Final Communiqué, 7-8 October, www.oecd.org/newsroom/46163626.pdf, OECD, Paris (read on 28th Aug 2016).

available for AtlasTI)	Science Foundation,	better health outcomes ABDGH	and social care	personally controlled health records personalized medicine privacy and security big data ICT to support smarter models of care	
STUDY	Policy /policy topic introducers	Main background policy	role of ICT, eHealth policy	Implementation policy	JAseHN
Health Data Governance PRIVACY, MONITORING AND RESEARCH (P1)	the OECD HCQI (Health Care Quality Indicators) Expert Group as part of the 2013/14 programme of work of the OECD Health Committee. The OECD Working Party on Security and Privacy in a Digital Economy (SPDE) provided input, HCQI Advisory Panel of Experts on Health Information Infrastructure (APHII)	improve the health outcomes of patients and the quality and performance of the health care systems improve research BDI	privacy-protective uses of personal health data,	data governance framework that enables privacy-protective data use data linkage, sharing of data, secondary use of data, safety, privacy accreditation/certification, transparency internatio nal collaboration	
DRAFT OECD GUIDE TO MEASURING ICTs IN THE HEALTH SECTOR (P5)	An OECD Expert Group representing 30 countries *(including* EC, WHO) and BIAC (Business and Industry Advisory Committee) co-financed with grants by Health Canada, the Commonwealth Fund (CMW), the European Commission (Directorate General for Health and Consumers and Directorate General Connect), the Ministry of Health of Spain, the German Federal Health Ministry, and the Office of the National Coordinator for Health Information Technology (ONC) at the US	improve the functioning of healthcare systems and the health of the population. 1, Increase the quality and efficiency of care; (2) Reduce the operating costs of clinical services; (3) Reduce the administrative costs of running the healthcare system; and (4) ABDE	availability and effective use of ICTs	timely access and sharing of patient data via EPRs research New ways of delivering care effective public health planning, and the evaluation of healthcare interventions and their quality monitor progress of e-health strategies, Enable entirely new models of healthcare deliver	WP 7 monitoring strategies
Big Data for Advancing Dementia Research: An Evaluation of Data Sharing Practices in Research on Age-related Neurodegenerative Diseases" (2015) (not assessed in Atlas TI)	G8 health ministers mandated the OECD to report. Reported to the World Dementia Council and presented to the G7 health ministers at the First WHO Ministerial Conference on Global Action Against Dementia	Promote research that would improve dementia prevention and care DI	More use of EPR*s and registers, data governance	data linkage, privacy, data governance	eID, Guidelines on Patient registers, WP5, Secondary use of data WP 7

~~Toward New Models for Innovative Governance of Biomedicine and Health Technologies.~~		~~Better Health through Biomedicine: Innovative Governance~~	~~None~~	~~governance~~	

Search results on OECD eHealth studies

Directly eHealth related

Improving Health Sector Efficiency: The Role of Information and Communication Technologies." *Directorate for Employment, Labour and Social Affairs, Health Division* OECD, 2010. http://www.oecd-ilibrary.org/social-issues-migration-health/improving-health-sector-efficiency_9789264084612-en

Achieving Efficiency Improvements in the Health Sector Through the Implementation of Information and Communication Technology. (The link leads to the OECD study nr.1) http://ec.europa.eu/health/eu_world/docs/oecd_ict_en.pdf

ICTs and the Health Sector TOWARDS SMARTER HEALTH AND WELLNESS MODELS. OECD 2013. http://www.oecd-ilibrary.org/science-and-technology/icts-and-the-health-sector_9789264202863-en

Strengthening health information infrastructure for health care quality governance. Good Practices, New opportunities and Data privacy protection challenges. OECD health policy studies series, June 2013. http://www.oecd-ilibrary.org/social-issues-migration-health/strengthening-health-information-infrastructure-for-health-care-quality-governance_9789264193505-en

Health Data Governance PRIVACY, MONITORING AND RESEARCH. OECD Health Policy Studies, OECD Publishing, Paris, 2015. http://dx.doi.org/10.1787/9789264244566-en (+ Policy brief)

DRAFT OECD GUIDE TO MEASURING ICTs IN THE HEALTH SECTOR.COM/DELSA/DSTI(2013)3/FINAL DIRECTORATE FOR EMPLOYMENT, LABOUR AND SOCIAL AFFAIRS DIRECTORATE FOR SCIENCE, TECHNOLOGY AND INDUSTRY OECD (2015) http://www.oecd.org/health/health-systems/Draft-oecd-guide-to-measuring-icts-in-the-health-sector.pdf. Related documents:

Adler-Milstein J1, Ronchi E, Cohen GR, Winn LA, Jha AK. Benchmarking health IT among OECD countries: better data for better policy. J Am Med Inform Assoc. 2014 Jan-Feb;21(1):111-6. doi: 10.1136/amiajnl-2013-001710. Epub 2013 May 30. http://www.ncbi.nlm.nih.gov/pubmed/23721983

OECD model survey on ICT availability and use in the health sector – report on pilot as of October 2015 (not publicly available, access via Hannele and Päivi's own files)

Benchmarking Deployment of eHealth among General Practitioners (2013). http://ec.europa.eu/digital-agenda/en/news/benchmarking-deployment-ehealth-among-general-practitioners-2013-smart-20110033 and European hospital survey: Benchmarking deployment of eHealth services 2012-2013

The EC benchmarking activities in the eHealth field are complemented with a multi-stakeholder initiative to improve the availability and quality of health ICT data and indicators. It is led by the Organisation for Economic Co-operation and Development (OECD) with the participation of the European Commission, the

World Health Organization and further stakeholders including industry and health authorities representatives. This initiative decided to focus measurement activities on fourteen possible benchmarking sub-indicators, mostly falling into the following four higher level dimensions: a) Electronic Health Records (EHR); b) Health Information Exchange (HIE); c) Personal Health Records (PHR); and d) Telehealth. Furthermore, they have highlighted that availability and use of ICTs are two distinct issues and both need to be captured in measurements (Adler-Milstein,Ronchi et al. 2013). The design of the questionnaires for the two latest EC benchmarking exercises (for GPs and hospitals), took account of these recommendations.

Big Data for Advancing Dementia Research: An Evaluation of Data Sharing Practices in Research on Age-related Neurodegenerative Diseases" (2015), ", OECD Digital Economy Papers, No. 246, OECD Publishing. http://dx.doi.org/10.1787/5js4sbddf7jk-en

Toward New Models for Innovative Governance of Biomedicine and Health Technologies. http://www.oecd-ilibrary.org/science-and-technology/toward-new-models-for-innovative-governance-of-biomedecine-and-health-technologies_5k3v0hljnnlr-en

(Developing an E-Health Strategy. A Commonwealth Workbook of Methodologies, Content and Models. 2011 http://www.thecommonwealth-ilibrary.org/commonwealth/social-issues-migration-health/developing-an-e-health-strategy_9781848590830-en (not available in electronic format. Not an OECD study, but done in collaboration with the OECD)

Global eHealth – Measuring outcomes: why, what and how. Report Commissioned by the World Health Organization's Global Observatory for eHealth (2008) http://www.ehealth-connection.org/files/conf-materials/Global%20eHealth%20-%20Measuring%20Outcomes_0.pdf Not an OECD document, nor a study, but shows connection between the OECD and WHO eHealth activities, and forms a basis for OECD eHealth benchmarking activities

Studies with Health focus, which have eHealth content

Health at a Glance 2015 : OECD Indicators. http://www.oecd-ilibrary.org/content/book/health_glance-2015-en

Improving Value in Health Care. MEASURING QUALITY. OECD Health Policy Studies 2010. http://www.oecd-ilibrary.org/social-issues-migration-health/improving-value-in-health-care_9789264094819-en

Fiscal Sustainability of Health Systems. Bridging Health and Finance Perspectives. OECD 2015 http://www.oecd-ilibrary.org/social-issues-migration-health/fiscal-sustainability-of-health-systems_9789264233386-en

Medical Tourism: Treatments, Markets and Health System Implications: A scoping review http://www.oecd.org/els/health-systems/48723982.pdf

A System of Health Accounts. 2011 Edition http://www.oecd-ilibrary.org/social-issues-migration-health/a-system-of-health-accounts_9789264116016-en

Working Party on International Trade in Goods and Trade in Services Statistics: Improving estimates of international trade in health services under A System of Health Accounts November 7-9, 2011, PARIS www.oecd.org/std/its/49048719.ppt

Tele-medicine, e-health, etc; Patient mobility : planned, unplanned care (tourists, students, workers, etc); Health professionals abroad. Collective care…

Health Reform. Meeting the Challenge of Ageing and Multiple Morbidities. http://www.oecd-ilibrary.org/social-issues-migration-health/health-reform_9789264122314-en

Fiscal Sustainability of Health Systems. Bridging Health and Finance Perspectives. http://www.oecd-ilibrary.org/social-issues-migration-health/fiscal-sustainability-of-health-systems_9789264233386-en

Studies focusing on economy

Exploring the Economics of Personal Data A SURVEY OF METHODOLOGIES FOR MEASURING MONETARY VALUE. http://www.oecd-ilibrary.org/science-and-technology/exploring-the-economics-of-personal-data_5k486qtxldmq-en

Exploring Data-Driven Innovation as a New Source of Growth: Mapping the Policy Issues raised by "Big Data" http://www.oecd-ilibrary.org/science-and-technology/exploring-data-driven-innovation-as-a-new-source-of-growth_5k47zw3fcp43-en

Data-driven Innovation for Growth and Well-being (2015) http://www.oecd-ilibrary.org/science-and-technology/data-driven-innovation_9789264229358-en

OECD Internet Economy Outlook 2012. (especially chapter on Government priorities and policy developments) http://www.oecd-ilibrary.org/science-and-technology/oecd-internet-economy-outlook-2012_9789264086463-en

OECD Information Technology Outlook 2010. http://www.oecd-ilibrary.org/science-and-technology/oecd-information-technology-outlook-2010_it_outlook-2010-en

OECD Science, Technology and Industry Scoreboard 2013. http://www.oecd-ilibrary.org/science-and-technology/oecd-science-technology-and-industry-scoreboard-2013_sti_scoreboard-2013-en

10. Annex – Quotations from original reports

4 OECD Incentives to reach policy goals

Study (1) concludes that there are a number of practices or approaches that could usefully be employed in efforts to improve and accelerate the adoption and use of health ICTs. As these typically imply trade-offs with competing goals, policy makers must determine whether the expected benefits from these practices are likely to outweigh the costs in a particular situation. This study, however, highlights an absence, in general, of independent, robust monitoring and evaluation of programmes and projects. While most of the case studies had included some sort of formal evaluation to justify initial budgets, few had conducted a formal post-implementation evaluation to determine the actual payoff from the adoption and use of ICTs. (4:22)

4.1 Health Ministry leadership - data governance

Only with strong health data governance frameworks can governments safely enable data use to improve health care quality and performance. Eight key data governance mechanisms support strengthening national health information systems and enabling multi-country projects to improve the public's health.(2:7)

According to Study (4) Health data collected by national governments that can be linked and shared are a valuable resource that can be used safely to improve the health outcomes of patients and the quality and performance of the health care systems that serve them. Data allowing a comprehensive view of health care services permit uncovering medical errors, adverse drug reactions, fraud, adherence to clinical guidelines, effective treatments, optimal care paths and optimal responders to treatment. (1:271)

Study 4 emphasizes the necessity of Health Ministry leadership to ensure that delivering the data to manage this important sector. It is regarded to be at the forefront of government policy and action(1:272)

Study 4 supports OECD countries in developing privacy-protective uses of personal health data by examining current data availability, uses and governance practices; and identifying key data governance mechanisms that maximise benefits to patients and to societies and minimise risks to patients' privacy and to public trust and confidence in health care providers and governments. Study 4 identifies (1:273)

Study 4 identified Eight key data governance mechanisms to support strengthening national health information systems and enabling multi-country projects to improve the public's health.: mechanisms (2:1)

9. The health information system supports the monitoring and improvement of health care quality and system performance, as well as research innovations for better health care and outcomes.
10. The processing and the secondary use of data for public health, research and statistical purposes are permitted, subject to safeguards specified in the legislative framework for data protection.
11. The public are consulted upon and informed about the collection and processing of personal health data.

12. A certification/accreditation process for the processing of health data for research and statistics is implemented.
13. The project approval process is fair and transparent and decision making is supported by an independent, multidisciplinary project review body.
14. Best practices in data de-identification are applied to protect patient data privacy.
15. Best practices in data security and management are applied to reduce re-identification and breach risks.
16. Governance mechanisms are periodically reviewed at an international level to maximise societal benefits and minimise societal risks as new data sources and new technologies are introduced(1:277)

4.2 Direct regulation (privacy and security)

A robust and balanced approach to privacy and security is essential to establish the high degree of public confidence and trust needed to encourage widespread adoption of health ICTs and particularly EHRs. Government action is needed to help establish reliable and coherent privacy and security frameworks and accountability mechanisms that both encourage and respond to innovation. (4:26)

Health information can be extremely sensitive and professional ethics in health care demands a strict adherence to confidentiality. A view held by many physicians in nearly all the case studies (1) was that sharing identifiable patient data among different providers in a network raises the question of who should be allowed access to the file and how such access is to be regulated and by whom. There appears to be a generalised need for clear and enforceable rules on these sensitive issues. Patient consent was also often identified as the main "road block" to creating a co-ordinated information system for patient care. Some of the case study countries require that patients be informed at the time of data collection of all the purposes for which their data may be used. Others, operate on the basis of an implied consent model for disclosure of health information for treatment purposes, coupled with the individual's right to object to disclosure (opt out). The mplementation of privacy and security requirements is proving particularly challenging in the case of EHRs and constitutes a main barrier to system-wide exchange of information in many countries. (4:20)

There are separate regimes for public sector and private sector organisations and specific legislation applicable to entities which hold health records. Many OECD countries are in the early stages of health ICT adoption, and this provides a critical window to address privacy and security issues(4:21)

4.3 Economic instruments

Grants and subsidies are the most common form of financial incentives. Bonuses or add-on payments that reward providers for adopting and diffusing ICTs are also often used, particularly in countries where physicians are remunerated on the basis of fee-for-service. OECD findings suggest that one-off subsidies or grants, while essential to start-up initiatives, may do little to support ongoing ICT use and will not have a lasting impact unless other potentially conflicting incentives (e.g. through payment schemes such as FFS) are modified or removed, and the business case for the initiative is clearly defined. The long-term sustainability and financing issues appear to be the most challenging and, in most cases, unknown aspects of the ICT initiatives reviewed in this report. (REF)

In the case studies reviewed in report 1, policy approaches that link financial incentives (e.g. bonus payments) to the adoption and use of ICTs for specific tasks or conditions where the public health benefit is recognised from the very start have proven particularly successful. Payers' willingness to differentially reward improved quality of care through the use of ICTs is key not only to future sustainability but central to shared reaping of benefits from the investments made. The financial incentive packages in these countries are designed to "insulate" physicians from potential productivity and upfront financial losses from adoption of ICTs. At the same time, they operate to maximise social benefit and act as catalyst of change by requiring (or promoting) electronic data collection and reporting on quality improvement activities.(4:16)

4.4 Persuasive measures

These include support measures such as providing education and training for change management). (4:5)

4.5 Achieving commonly defined and consistently implemented standards

While health care organisations have access to an ever-increasing number of information technology products, "linkages" remain a serious problem. To move the interoperability agenda forward, many governments have set up specific bodies or agencies to co-ordinate standard-setting and have developed strategies at the national level. Under pressure, vendors and users, as well as international standards organisations, have also started to collaborate more openly in the development and progression of standards. However, even when standards are available, they are often applied in different ways by different institutions. Additional mechanisms are needed to promote their consistent implementation in a manner that achieves interoperability. Besides technological specifications, appropriate incentives, consensus-building and other enabling policies all have to be in place. Although these initiatives all appear very promising, there is still limited evidence that they have significantly improved interoperability (4:5)

4.6 Establishment of a formal health care ICT product certification processes

A variant to financial incentives approach, is to establish a certification process that targets vendors' products and services, and includes a number of "usability" requirements such as service levels, technical support responsiveness, financial viability, etc. (4:6)

Certification is an additional mechanism to standards-approach. Even when standards are available, they are often applied in different ways by different institutions. Additional mechanisms are needed to promote their consistent implementation in a manner that achieves interoperability. Besides technological specifications, appropriate incentives, consensus building and other enabling policies all have to be in place. Four of the case study countries (Netherlands, Spain, Sweden, and the United States) have, therefore, established formal health care ICT product certification processes. In several of these countries, health care payers, ranging from governments to the private sector, are now also offering, or setting out to offer, financial incentives for the adoption of certified EHRs. A variant to this approach, implemented at present only in Canada in a few provinces, has been to establish a certification process that targets vendors' products and services, and includes a number of "usability" requirements such as service levels, technical support responsiveness, financial viability, etc. This process is a targeted effort, within the context of a specific incentive programme to promote EMR/EHR adoption, rather than a broad product certification scheme, as envisaged in the other countries. Although these initiatives all appear very promising, there is still limited evidence that they have significantly improved interoperability. (4:19)

4.7 Acting as Leaders of ICT projects

In case studies, Governments also occupied a central position as initiator, funding provider, project facilitator, and neutral convener. Governments, therefore, may be the only source of leadership to enable the effective use of ICTs to implement new directions for health system change and redesign (4:14) OECD governments are evidently using their leverage as purchasers and payers to drive ICT adoption, which reflects the growing consensus about the vital "public good" to be expected from improved health information exchange. (4:15)

4.8 Aligning incentives with intended benefits

To achieve the intended benefits from ICT technology, governments and payers need to set targets associated with unambiguous public health gains such as improved management of highly prevalent chronic diseases which are strongly associated with preventable hospitalisations, and better align resources, processes, and physician compensation formulae to match the nature of the gains to be achieved. To do this it is necessary to address the fixed costs associated with setting up the system. More important, and more difficult, it is also necessary to ensure that health ICTs are used effectively to deliver evidence-based care leading to better outcomes. This requires what has been termed, for want of a better phrase, a "sustainable business model" which either adapts, or takes into account, the payment systems in place for health care services more generally.(4:27)

Study (4) illustrates Alignment of incentives and fair allocation of benefits and costs as one prerequisite for successful implementation and widespread adoption of the ICTs. Since the costs and benefits associated with adopting new technologies are not shared equitably among stakeholders, investments which are cost-effective from the point of view of the system as a whole are not automatically going to be undertaken (4:6)

5 OECD Working methods

In the Qualitative data analysis conducted by AtlasTI, several working methods to generate knowledge were identified. Below quotations from studies, grouped under the types of methods generated in the analysis

5.1 In-depth investigations

To support OECD countries in improving data governance frameworks, health ministries and data privacy protection experts in OECD countries collaborated in 2013/14 to pursue an in-depth investigation (4) to understand the current situation, to uncover and document practices, and to identify promising data governance mechanisms that enable privacy-protective monitoring and research. Advice and guidance on all aspects of this study were provided by a multi-disciplinary panel of experts. (1:275)

5.2 Expert groups

In order to develop a model survey for benchmarking ICT's in the health sector, an OECD Expert Group representing 30 countries (including India, Brazil, and Egypt, as well as the European Commission (EC), the World Health Organisation (WHO) and BIAC (Business and Industry Advisory Committee) and four expert sub-groups or Task Forces, chaired respectively by J. Zelmer (Canada), P. Hämäläinen (Finland), M. Sprenger (the Netherlands), J. Thorpe (United Kingdom) brought a range of relevant expertise and country representation to this initiative. Within the OECD Secretariat, this project was developed by Elettra Ronchi who acted as project manager and coordinator. The project was carried out in close cooperation with Dr

Ashish Jha (Harvard University School of Public Health), who led this effort as Chair of the virtual OECD Expert Group on benchmarking health information and technologies, and Julia Adler-Milstein (University of Michigan).(7:2)

The Advisory Panel of Experts on Health Information Infrastructure identified key data governance mechanisms supporting privacy-protective data use (1:276)

5.3 Pilot projects

The Model Survey and the Methodological Guidelines for benchmarking ICTs in the health sector have been pilot tested by the European Commission and the Brazil Center for Studies on ICTs (CETIC) in 2013 They will be tested in 2014-2015 by an additional nine pilot countries (Canada, Denmark Finland, Germany, Israel, The Netherlands, South Korea, Switzerland, and The United States). The ICT working group of the Statistical Conference of the Americas of the Economic Commission for Latin America and the Caribbean (ECLAC) adopted in 2014 the OECD Model Survey framework in the development of a regional survey for the measurement of availability and use of ICTs in the health sector and its methodological recommendations.(ref)

5.4 Provision of guidelines

Legislations and privacy policies have been influenced by the 1980 publication of the OECD privacy guidelines and these guidelines are recognised as representing "the international consensus on privacy standards and providing guidance on the collection of personal information in any medium" (OECD, 2009). The OECD guidelines emphasize that data collections are respectful of the protection of personal privacy when they follow eight guiding principles (Box 3.1). In 2013, the OECD revised these guidelines; however, the eight guiding principles remain relevant and were unchanged (OECD, 2013). (1:79) Study 4 depicted OECD guidelines for protection of privacy and the transborder flow of personal data (figure xx) (1:303)

The Eight key data governance mechanisms to support strengthening national health information systems and enabling multi-country projects to improve the public's health also provide one type of guideline (2:1)

5.5 Provision of tools

An OECD Guide to Measuring ICTs in the Health Sector was developed with the aim to provide a standard reference for statisticians, analysts and policy makers in the field of health Information and Communication Technologies (ICT). The objective is to facilitate cross-country data collection, comparisons and learning on the availability and use of health ICTs. (5:1)

To support balanced decision making about the approval of projects involving the processing of personal health data, a Risk-Benefit Evaluation Tool is also provided (1:278)

6 OECD study results on eHealth

In the following section, quotations from the studies related to four key eHealth outcome categories are presented, grouped into the four category types from the framework as presented in the "scope of the work".

6.1 Quotations for specific eHealth policy targets

6.1.1 Improving efficiency and quality of care

In 2010, an OECD survey of countries identified four core objectives for ICT implementation: (1) Increase the quality and efficiency of care; (2) Reduce the operating costs of clinical services; (3) Reduce the administrative costs of running the healthcare system; and (4) Enable entirely new models of healthcare delivery. (OECD, 2010) (5:5)

Essential to health care quality and performance assessment is the ability to follow patients as they progress through the health care system from primary health care to speciality care to hospitalisations, long-term care, home care, hospice care and death. These data should also provide information about underlying patient characteristics, illnesses, medications, therapies, tests and images. This type of follow-up permits a comprehensive view of health care services provided and the health outcomes of those services; and permits uncovering medical errors, adverse drug reactions, fraud, adherence to clinical guidelines, effective treatments, optimal care paths and optimal responders to treatment.(1:355)

6.1.2 Performance-based governance

Health Ministry leadership is necessary to ensure that delivering the data to manage this important sector is at the forefront of government policy and action. Effective collaboration between health ministries, justice ministries and data privacy regulators is essential if governments are to evolve toward a situation where societal benefits from data use are maximised and risks to society from data use are minimised. At the same time, government needs clear and open channels to engage with stakeholders in the development and use of data, so that data governance frameworks and practices reflect societal values and priorities.(1:164)

According to study 4, there is a need of a good governance framework for personal health data (2:7) OECD countries are ageing and increasing shares of our populations are living longer with multiple chronic and disabling conditions. This shift is placing pressure on limited health care resources. To meet this challenge, health system managers and policy makers are moving toward performance-based governance to improve care quality, co-ordination and efficiency. Performance-based governance requires timely and accurate patient data that span the continuum of care, including health outcomes and costs. Such data also support re-designing and evaluating new models of health care service delivery and contribute to the discovery and evaluation of new treatments. (1:270)

To support OECD countries in improving data governance frameworks, health ministries and data privacy protection experts in OECD countries collaborated in 2013/14 to pursue an in-depth investigation into health data governance including the development and use of personal health data in OECD countries and the legal frameworks, policies and practices that are in place to protect the privacy of data subjects when data are being processed and analysed.(1:20)

6.1.3 EHR implementation

In the 2013 study, 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. (3:283)

Study conducted in 2013 revealed that 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 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.(3:286)

6.1.4 Enabling data use for secondary purposes

On 7-8 October 2010, Health Ministers met in Paris to discuss how to improve value in healthcare. In their final communiqué, they underlined the importance of better health information systems and called for more and effective use of health data that has already been collected. Ministers also noted that expanded use of health information and communication technologies (ICTs), particularly electronic health records, can help to deliver better quality of care, reduce medical errors and streamline administration. They recognised the need to reconcile the legitimate concerns of citizens to protect their privacy with the use of health data to improve health sector performance and the quality of care. (3:74)

In 2012, most countries reported a national plan or policy to implement electronic health records (22 of 25 countries) and most had already begun to implement that plan by 2012 (20 countries) (OECD, 2013a; OECD, 2015). At that time, the implementation was relatively new in virtually all participating countries, having started within the previous four years. Of the 25 countries studied, 18 countries had included some form of secondary analysis of electronic health records within their national plan. The most commonly included secondary uses reported by 15 countries were public health monitoring and health system performance monitoring. Fourteen countries also indicated that they intended for physicians to be able to query the data to support treatment decisions. The least commonly-reported planned data use was for facilitating or contributing to clinical trials. This use was noted by ten countries. Many countries also reported that regular use of electronic health record data for secondary analyses were already underway. Public health monitoring (13 countries) and general research (11 countries) were the most commonly reported uses.(1:40)

Health data collected by national governments that can be linked and shared are a valuable resource that can be used safely to improve the health outcomes of patients and the quality and performance of the health care systems that serve them. Data allowing a comprehensive view of health care services permit uncovering medical errors, adverse drug reactions, fraud, adherence to clinical guidelines, effective treatments, optimal care paths and optimal responders to treatment (1:271)

6.1.5 Ensuring interoperability in order to link different datasets

According to study 4, Essential to health care quality and performance assessment is the ability to follow patients as they progress through the health care system from primary health care to speciality care to hospitalisations, long-term care, home care, hospice care and death. (1:283)

Health data should provide a picture of the care pathway, *linking different datasets.* Understanding pathways often requires linking datasets at the patient level, as current health data are usually

collected in silos such as primary health care datasets, datasets of in-patient hospitalisations, long-term care datasets, disease registries, pharmaceutical datasets and death registries. As a result, datasets must have sufficient detail to enable valid and reliable dataset linkages. Further, in most countries, key areas of health care including primary care, long-term care and prescription medicines are not being included in data linkages to regularly monitor quality and health system performance (2:5)

6.1.6 Protecting data privacy and security

Managing the safe use of health data is a major concern across the OECD (2:3) Concerns about protecting patient privacy have limited sharing of personal health data (2:5) This requires assessing the risks and benefits of use of personal data in health (2:6) The need to more actively manage health system outcomes will drive health systems toward greater use of clinical and administrative data to assess the comparative effectiveness of therapies and services. These data will also be needed to support re-designing and evaluating new models of health care service delivery and to contribute to the discovery and evaluation of new treatments. (1:281)

All countries can improve their health information systems and make better use of data for quality, safety and performance gains and to advance medical treatments and practices (...) Only with strong health data governance frameworks can governments enable data use and do it safely to improve health care quality and performance" (2:8).

Managing the safe use of health data is a major concern across the OECD. In the absence of a national strategy to promote safe data use and without a strong health data governance framework, many countries will miss the opportunity to safely enable data use to improve health care quality and performance.(2:4)

Concerns about *protecting patient privacy* have limited sharing of personal health data.(2:6). The development of the European Regulation on Data Protection which had not yet entered into force during data collection was causing uncertainty with respect to how it may impact upon existing health information systems (Finland) and on data linkages and data anonymisation specifically (Spain). A group of countries are unsure if they will be able to extract data from electronic health record systems to monitor the quality of care within the next five years, either because more time will be needed or changes in policy will be needed.(1:367)

Secondary use of health data calls for assessing the *risks and benefits of use of personal data* in health (2:7) Data de-identification methods that are satisfactory today will need to be revised with the introduction of new technologies, new health data and new data privacy protection risks.

The development and publication of policies or guidelines either at the national level or at the data custodian level greatly increases public transparency regarding the steps that are taken to protect health information privacy and security and provides a means to improve consistency within and among dataset custodians and a basis from which training courses and materials can be developed. International efforts, such as the standards and guidelines set by the International Standards Organisation regarding privacy and security requirements of EHR systems (ISO/TS 14441:2013); security of electronic health records communications (ISO/TS 13606-4:2009); and data protection to facilitate transborder flows of personal health data (ISO 22857:2011); support harmonisation of national data security and privacy protection practices. Country experts provided examples of the guidelines and policies that have been developed to protect data privacy and security.

6.1.7 Open government health data

Countries participating in study 4 were asked if their government had a policy or a programme in place to promote open government health data. Overall, such initiatives were signalled within twelve countries: Canada, Finland, Iceland, Italy, Korea, New Zealand, Singapore, Sweden, Switzerland, Turkey, the United States and the United Kingdom (Table 4.1). Reasons for these initiatives include to be more transparent to the public and to make it easier for government data to contribute to policy making, administration, consumer knowledge, business innovation, and so on. Each initiative is described in Table 4.1. (1:224)

Often the policy or programme to promote open government health data is part of a public-sector wide initiative. Countries rarely, however, provide the public with a centralised location where they can inform themselves about all of the national health datasets, and, in particular, the national personal health datasets. Some countries provide the public with information regarding approved studies involving the processing of personal health data including dataset linkages. This information increases public transparency about how personal health datasets are being used, by whom and for what objectives. Countries supporting researcher access to data tend to be more transparent with the public about data access by providing, usually via a website, information about applying for data access, project approval requirements and legal and practical requirements of approved applicants. Such transparency enables the public to understand and scrutinise data access practices and safeguards and offers fairer access to information to potential data users, whether they are located in the country or abroad. The United Kingdom shares an important lesson-learned about the necessity of public consultation and effective public communications that must accompany national plans to strengthen health information infrastructure and national efforts to develop data governance that maximises societal benefits and minimises societal risks.(1:357)

Aims of open health data initiatives and transparency vary (1:356) While many countries reported having a whole of government strategy to improve openness and transparency, countries rarely provide the public with a centralised location where they can inform themselves about all of the national health datasets, and, in particular, the national personal health datasets. Transparency about the existence of personal health datasets would greatly enhance public awareness of health data and its uses and would stimulate interest in data-based research. Public information should include a description of datasets' content, uses, custodians, privacy and confidentiality safeguards, application procedures, approval processes and current projects (1:358)

Some countries provide the public with information regarding approved studies involving the processing of personal health data, typically dataset linkages. Such information increases public transparency about how personal health datasets are being used, by whom and for what objectives. It enables the public to scrutinise data uses and it inspires new ideas for projects involving health data for the public benefit. (1:359)

In the United Kingdom, England, there is a cross-government policy to promote transparency and open data (1:96) In many ways the United Kingdom has a strong policy toward openness and transparency about data and data access. Nonetheless, and perhaps because of this openness, it also has experienced difficulties that provide lessons-learned about the necessity of strong public communications that must accompany openness and transparency initiatives. (1:360)

The Advisory Panel of Experts on Health Information Infrastructure identified the following key elements of the governance of health data that promote openness and transparency:
3. The public are consulted upon and informed about the collection and processing of personal health data. Public engagement
a) Includes regular, clear and transparent communication with the public about the collection and processing of personal health datasets including the benefits of the processing, the risks of the processing and the risk mitigations.
b) Includes public information, such as a website, that describes personal health datasets at a national level, including the content of the datasets and the dataset custodians.
c) Includes public information, such as a website, that describes applications for approval of the processing of national personal health datasets, including dataset linkages, as well as approval decisions. (1:361)

6.1.8 Centralisation of personal health data collection and processing

Whether by policy or by default, some countries have concentrated the collection and processing of key national personal health datasets. As a result, they have distinct advantages in the further development of these data for statistics and research, in the undertaking of approved data linkages studies and in organising and improving secure access to data for external researchers and public bodies. This chapter discusses current concentration of national dataset processing and the introduction of accreditation or certification for central data processors and the implications for the protection of health data privacy and the accessibility of data for approved research and statistics (1:362)

The greatest concentration of national health datasets is in Switzerland and Turkey where all key national datasets are in the custody of the same organisation (Table 5.1). Ninety per cent of national datasets are within one organisation in Iceland and Japan. Other countries with a high proportion of national datasets concentrated in one custodian are the United Kingdom (Scotland) at 78% followed by Denmark (75%), New Zealand (75%), the United States (73%), the Czech Republic (71%), and Sweden (70%)(1:263) Half of the countries in this study regularly conduct data linkages of all of their key national datasets within a single organisation (1:364)

There have been recent efforts in the United Kingdom and Australia to introduce an accreditation process for organisations wishing to process health data. Accreditation provides a means to establish detailed data governance criteria that accredited organisations must meet, to independently verify that the requirements are satisfied before granting accreditation status and to audit organisations that are accredited for compliance.(1:365)

It is worth noting that there is a significant difference in resource expenditures between countries where there is a unique patient identifying number that is widely used and accurately captured within key national health datasets and those where there is a need to rely upon a set of potential identifying variables in order to establish a dataset linkage for statistics and research. In the former, providing data linkage services can be a routinised and automated process requiring few resources. In the latter, data linkage services require skilled statisticians and considerable time to execute accurately (1:366)

6.2 Interoperability

The term interoperability was mentioned 129 times in the analysed 4 main OECD studies, of which main focus was in studies ref. 3 and ref.4. There has been a growing consensus that any national EHR strategy should go hand-in-hand with efforts to achieve system-wide secure

exchange of health information, if it is to realise the promise of ICTs. This, in turn, crucially depends on compliance with standards and interoperability. (4:67)
It is defined as the ability of two or more systems to exchange information and to make use of exchanged information. It is an essential pre-condition to the development of electronic health records from the electronic medical records within multiple health care organisations (P3:3) Different computer systems are said to be interoperable when they can exchange data with and use data from other systems. Simply converting data from a paper format to a digital format is not enough to ensure interoperability. Interoperability depends primarily on all the computer systems that need to exchange information being able to communicate. The rules that specify how to send information back and forth need to be defined. This obviously involves technology issues, but it also includes other kinds of issues, such as legal and business rules that need to be co-ordinated between organisations in order for them to feel comfortable exchanging confidential patient data (Chaudhry, 2005).(4:46)

To clarify the potential value of health information exchange (HIE) and interoperability a conceptual framework describing how health care entities can share information has been developed by the Center for Information Technology Leadership (CITL). This provides a functional taxonomy based on three factors in data exchange: the amount of human involvement, the sophistication of the ICT, and the adoption of standards (4:58). Study from 2010 presents four levels of interoperability (4:61),There is some value to be gained at every stage in a progressive shift to full interoperability, particularly if high clinical value areas are targeted first (4:55).

Level	Attributes
1	Non-electronic data – no use of ICT to share information. The most commonly used manual process for sharing information is either in writing or orally. Human facilitation is exclusively relied upon to aggregate, review, and abstract data from paper sources. Examples: postal mail, phone
2	Machine transportable data – transmission of non-standard information via basic ICT; information within the document cannot be electronically manipulated. Clinicians can access the information, but no computerised data processing or logic can be applied. Examples: PC- based exchange of scanned documents or manual faxing, pictures, portable document format (PDF)
3	Machine-organisable data – transmission of structured messages containing non-standardised data; requires multiple interfaces that can translate incoming data from the each of the sending organisation's vocabulary to the receiving organisation's vocabulary; usually results in imperfect translations because the vocabularies used have incompatible levels of detail. Data content is indexed down to single fields, however human translation is required to convert actual data in each field from the vocabulary of the sending organisation to that of the receiving organisation. Examples: secure e-mail of free text, or PC-based exchange of files in incompatible/proprietary file formats, HL-7 messages
4	Machine-interpretable data – transmission of structured messages containing standardised and coded data; the ideal situation in which all systems exchange information using the same formats and vocabularies. All systems exchange data using the same messaging, format, and content standards, removing the need for multiple customised interfaces. All content can be extracted and converted electronically in each field and no longer requires human intervention. Examples: automated exchange of coded results from an external lab into a provider's EMR, automated exchange of a patient's "problem list".

Source: Center for Information Technology Leadership; Walker *et al.* (2005).

Table 2: Healthcare information exchange and interoperability taxonomy

The term interoperability is related to term Messaging standard. Messaging standards facilitate interoperability by defining how information will be communicated from one party to another. For example, Health Level 7 is a messaging standard for the exchange of clinical, financial and administrative data. (P3:4) It is also related to term Electronic Health Record: 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 (P3:5)

There no easy answer to any of the problems related to interoperability. Freely functioning private markets will not find a solution without public intervention. Indeed, authorities in the case study countries indicate that they are now intervening and in a number of ways (Table 4.1), though perhaps no single approach can produce the optimum outcome:
• Through government leadership in adoption of standards.
• Certification of products.
• By setting vendor conformance requirements along with incentives for use of interoperable systems.(4:68)

Area of focus	Australia	Canada	Netherlands	Spain	Sweden	United States
Certification of products	✖	✖	✓	✓	✓	✓
Standards-setting activities	✓	✓	✓	✓	✓	✓
Vendor conformance and usability requirements	✖	✓	✓ In proof of concept stage	✖	✖	✖

Source: OECD.

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Table 3: Measures to address lack of interoperability by country (4:70)

6.2.1 Legal and regulatory interoperability

The legislative framework is the foundation upon which a country's health information infrastructure may be developed and citizens' rights to health and to privacy codified. While health sector specific legislation is often developed in collaboration with national health authorities, legislation regarding the protection of the privacy of individuals and their personal information may be developed by justice ministries or other areas of government. As a result, it is of fundamental importance to health authorities planning to strengthen their health information infrastructure, that there is open dialogue across government regarding the legislative framework necessary to support maximising societal benefits from health data while minimising societal risks from data uses. (1:299)

Legislations and privacy policies have been influenced by the 1980 publication of the OECD privacy guidelines and these guidelines are recognised as representing "the international consensus on privacy standards and providing guidance on the collection of personal information in any medium" (OECD, 2009). The OECD guidelines emphasize that data collections are respectful of the protection of personal privacy when they follow eight guiding principles (Box 3.1). In 2013, the OECD revised these guidelines; however, the eight guiding principles remain relevant and were unchanged (OECD, 2013). (1:300)

These principles were subsequently reflected in the 1995 Data Protection Directive of the European Union (95-46-EC) that regulates the processing of personal information. Following the directive, European countries have implemented specific legislation relating to the protection of the privacy of personal information that complies with EU regulatory requirements. All of the European countries participating in this study report the existence of data protection legislation and an oversight body responsible for guidance and monitoring of this legislation in the form of a privacy or data protection office at the national level. While providing a unifying framework, the directive left considerable freedom to countries regarding whether to apply, restrict or extend the rules on processing sensitive data. In 2012, the European Union published a proposal for a new data protection regulation (European Commission, 2012).(1:301)

6.2.1.1 Legislation on adoption of EHRs conforming to national terminology

A challenge for all countries is to ensure that health authorities and health care providers implement the requirements of the national electronic health record system. Some countries have introduced, or are planning to introduce, laws or regulations that require health care providers to adopt and use electronic health record systems that conform to national requirements for clinical terminology and interoperability. This is a strong stimulus toward full participation of health care providers in the national HER system. In several countries, there are legal requirements to adopt electronic health records and adhere to standards.(3:40)

6.2.1.2 Legislation on Privacy and security

In a study conducted in 2010, A view held by many physicians in nearly all the case studies was that sharing identifiable patient data among different providers in a network raises the question of who should be allowed access to the file and how such access is to be regulated and by whom. There appears to be a generalised need for clear and enforceable rules on these sensitive issues.
Patient consent was also often identified as the main "road block" to creating a co-ordinated information system for patient care. Some of the case study countries require that patients be informed at the time of data collection of all the purposes for which their data may be used. Others, operate on the basis of an implied consent model for disclosure of health information for treatment purposes, coupled with the individual's right to object to disclosure (opt out). The implementation of privacy and security requirements is proving particularly challenging in the case of EHRs and constitutes a main barrier to system-wide exchange of information in many countries. In addition, in most of the case study countries, compliance is complicated by multiple layers of regulations from central to local. This is a particularly difficult problem in Australia, Canada, and the United States where rules for the protection of personal information have been established at both the national and local (state or province) levels. This made it especially difficult, for example, to implement a locally developed web-based electronic messaging and patient management system in Western Australia which cut across several jurisdictions. This is largely because rules for the protection of personal information have been established at both federal as well as state and territory levels in Australia. All regimes are similar but not identical (4:20)

According to study 4, there is a key national legislation that speaks to the protection of health information privacy in all countries participating in this study (Table 3.2). Most countries have more than one national legislation that governs aspects of health data privacy protections. In many countries there is both general data privacy legislation applying to all personal data and health-sector specific legislation providing greater clarity regarding the collection and use of personal health data. In some federated countries, including Canada and the United States, there are also provincial or state laws governing personal health data. (1:302)

Personal health data can, however, have inconsistent legislative protection. Gaps in some national legislative frameworks that create inconsistencies in privacy protection or result in some personal health data falling through the cracks and having no legislative protection, with case studies from Canada, New Zealand, US and Singapore. Throughout the OECD, the legal framework for the protection of personal data recognises health data as sensitive data and therefore requiring a high level of protection. There are particular variables within national health datasets, however, that may be considered to be of even higher sensitivity than other variables. Table 3.3 presents the types of variables that countries identified as being among the most sensitive within their national datasets. Variables that lead to the direct identification of individuals are highly sensitive, as are particular health conditions that may carry additional social stigma, namely selfharm, mental health conditions, sexually transmitted infections including HIV, substance use and treatment, sexual health, abortion, child abuse and homicide. (1:305)

6.2.1.3 Legislation/ policies on secondary use of health data

Legislation may permit the secondary analysis of personal health data in cases where patient consent is not possible or practicable. The secondary analysis of personal health data is typically permitted in countries with the consent of the data subject or when the analysis has been legally authorised. An important difference among countries is in whether or not the national legislation governing data privacy protection has recognised statistics and research as potential areas where an exemption to patient consent requirements could be granted. In these countries, an exemption can be granted for a proposed secondary use of personal health data that are in the public interest. In other countries where such exemptions are not legally permitted under the general data protection legislation, the general law may allow for a legally authorised exemption to patient consent requirements. In these countries, health-sector specific legislation may be introduced to clarify permitted uses of personal health datasets for statistics and research in the public interest. (1:336)

There are several significant differences between the 13 countries whose national plans or policies called for at least four different data uses (the engaged) and the twelve countries who were planning on fewer or no secondary data uses (the cautious). Engaged countries were somewhat more likely than cautious countries to report having created national governing bodies responsible for clinical terminology and interoperability standards, 62% compared with 50%. Terminology standards ensure that the data are captured in a consistent way with a structure that enables statistics and analysis. Interoperability standards ensure that records can be shared or exchanged.(1:41)

The case studies clearly indicate that appropriate privacy protection must be incorporated into the design of new health ICT systems and policies from the outset, because it is often difficult or impossible to introduce effective privacy protections retroactively. There are a variety of technical solutions already available to protect patients, but if privacy policies are unclear, technology will be of little help. Lack of clarity in the purpose and scope of privacy protection

may also have unintended perverse consequences. Although health care organisations have a strong interest in maintaining privacy and security, they also have to balance this interest against the need to ensure that information can be retrieved easily when required for care, particularly in an emergency.
Restoring public trust that has been significantly undermined is much more difficult than building it from the outset. Many OECD countries are in the early stages of health ICT adoption, and this provides a critical window to address privacy and security issues.(4:21)

As a case example, the state of Maine in the United States introduced in 1998 a privacy protection law that required written consent to disclose personal health data with few exceptions (Gellman, 2007). Written consent was required for all routine sharing of patient information among providers treating the same patient; for any disclosures to family members other than information about presence and general health condition during an emergency; and for payments. The introduction of the law was immediately followed by a strong expression of public dissatisfaction. Public objections to the law related to its restriction of disclosures to family members, the clergy, other physicians and the press. The law did permit disclosures for statistical and research purposes, and such disclosures were not the source of public discontent. A lesson learned in Maine was that disclosures only with consent are not necessarily what the public wants or expects. Instead, what is needed are practical ways for individuals to express their wishes regarding uses of their personal health data that do not impede their expectations for a workable health care system. The law was revised in 1999 to allow health care practitioners much more discretion to make disclosures without patient consent, including disclosures for treatment, payment activities and health care operations. The changes also made it easier to provide consent by adding oral consent as a new category and by allowing family members to authorise disclosures. (1:337)

In the 2013 study, Five countries were reported to have introduced or are planning to introduce legislation requiring health care providers to implement electronic health records that conform to national standards. (3:22)

6.2.2 Policy level interoperability

6.2.2.1 National body responsible for EHR infrastructure development + interoperability standards

The creation and analysis of national databases from electronic health records to improve the safety and efficiency of health care requires strong governance of the national electronic health record system. Of the 25 countries participating in the study, one-half have a national body that is responsible for EHR infrastructure development and for setting national standards for both the clinical terminology used within the records and the interoperability, or sharing, of records.(P3:21)

Once technical challenges are overcome and a system is capable of sharing information effortlessly and is interoperable, a policy decision needs to be made on how that information should be shared. As noted above, results of surveys and studies indicate that citizens are concerned about the privacy of their health information, and for good reason. As the contents of electronic health records are shared more widely, the risk increases that stigmatising disclosures could affect areas such as employment status, access to health insurance and other forms of insurance, and participation in community activities. Researchers have also noted that patients may engage in "privacy protective behaviors", avoiding screening tests, treatment, or taking part in research protocols if they are not confident that the privacy of their medical information is

adequately safeguarded (Goldman, 1998; Beckerman et al., 2008; G.W. School of Public Health and Health Services, 2009). (4:86)

Success strategies typically involve setting national standards for the content of the records, such as establishing a minimum set of data, where the content of the record follows terminology standards and the data is structured to be comparable; and setting interoperability standards, so that each electronic record system deployed in the country can speak to another. (3:23)

Study 4 examines results of the OECD study of 25 countries regarding the development of national bodies to oversee national EHR implementations. (3:60)

6.2.2.2 Standardisation

While health care organisations have access to an ever-increasing number of information technology products, "linkages" remain a serious problem. EHR systems must be interoperable, clinical information must still be meaningful and easy to decipher once transferred, whether between systems or between versions of the same software. It must also be gathered consistently if it is to permit effective secondary analysis of health data. Electronic capture of data through EHRs can facilitate clinical research, as well as improve evidence-based care delivery. The development of standards to enable interoperability continues to be a political and logistical challenge and a barrier to seamless exchange of information.(4:33)

Although, many of the standards required to progress toward interoperability do already exist (Hammond, 2008), there is still no international consensus around which standards should be adopted, and exactly how they are to be implemented. A lack of commonly defined standards and the consistent implementation of those standards continue to be a major impediment to setting up widely distributed interoperable systems. The need for standards has been recognised for a number of years now (Institute of Medicine, 2001; Government Accountability Office, 2005). However, the development, approval, and adoption of standards for health ICT are proving a difficult and drawn-out process.(4:51)

Health care providers struggle with inconsistent medical terminology, clinical records and data storage, as well as a multiplicity of schemes introduced to facilitate interconnection and communication between specific ICT systems. Because of fragmentation in the market and the rapidly evolving nature of technological solutions, in the absence of agreed industry-wide standards and compliance with existing rules, providers investing in technological infrastructure face high risks of failure and poor returns. The ability to share information (interoperability) is also entirely dependent on the adoption of common standards and compliance with them (4:32)

In a 2015 study, Development of standards for both semantics and for the interoperability of electronic health records across different health care settings is mentioned as some of the essential elements to implement national electronic health record systems (P3:6) Semantic Interoperability was identified by the advisory panel on experts on health information infrastructure as one of the key features of health information systems (P1:286)

The Advisory Panel of Experts on Health Information Infrastructure identified key features of high-value, privacy-protective health information systems, one of which is that the health information system Follows international standards for the coding of terminology and data interoperability.(1:287)

Figure 2.1 provides a high-level summary of the strength of the health information systems across OECD countries in 2013. The figure presents a score for each country that is the sum of the proportion of the key national personal health datasets investigated that meet seven different development and use criteria measured in this study (see Table 2.1),[one of which is use of standard codes for clinical terminology].

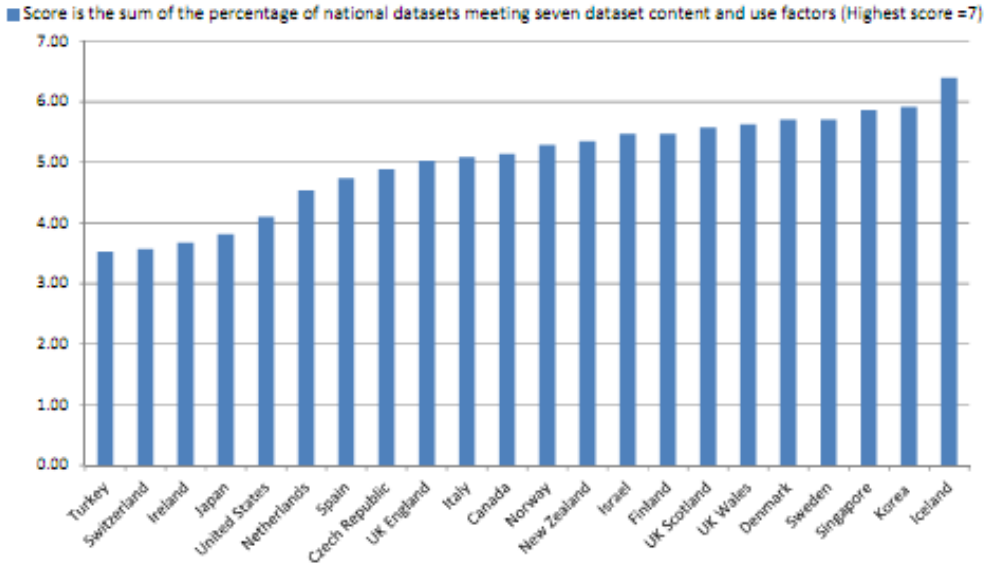

Figure 3: Key health data availability, maturity and use (1:335)

	% of key national health datasets available[1]	% of health care datasets with coverage of 80% or more of the population	% of available health care datasets where data extracted automatically from electronic clinical or administrative records	% of available datasets sharing the same unique patient ID	% of available datasets where standard codes are used for clinical terminology	% of available datasets used to regularly report on health care quality or health system performance (published indicators)	% of available datasets regularly linked for research, statistics and/or monitoring (indicators)	Total
Canada	71%	60%	63%	50%	100%	100%	70%	5.14
Czech Rep.	50%	50%	60%	86%	100%	71%	71%	4.89
Denmark	86%	90%	78%	92%	100%	75%	50%	5.70
Finland	79%	90%	44%	100%	89%	55%	91%	5.47
Iceland	79%	90%	90%	100%	100%	91%	90%	6.39
Ireland	57%	38%	60%	0%	100%	88%	25%	3.67
Israel	64%	55%	67%	89%	83%	100%	89%	5.47
Italy	64%	70%	86%	44%	100%	100%	44%	5.09
Japan	71%	68%	86%	50%	86%	20%	0%	3.81
Korea	79%	80%	88%	91%	100%	82%	73%	5.92
Netherlands	57%	50%	83%	58%	86%	67%	58%	4.54
New Zealand	57%	59%	86%	75%	83%	100%	75%	5.35
Norway	100%	50%	79%	93%	100%	50%	57%	5.29
Singapore	71%	80%	86%	100%	86%	70%	90%	5.86
Spain	36%	30%	75%	67%	100%	100%	67%	4.74
Sweden	86%	90%	89%	83%	89%	67%	67%	5.70
Switzerland	50%	47%	80%	43%	80%	43%	14%	3.57
Turkey	100%	73%	100%	0%	80%	0%	0%	3.53
United States	64%	13%	57%	84%	86%	73%	55%	4.11
UK England	64%	28%	100%	78%	100%	44%	89%	5.03
UK Scotland	57%	61%	86%	100%	75%	100%	78%	5.58
UK Wales	64%	65%	100%	100%	100%	44%	89%	5.62

1. Includes hospital in-patient data, mental hospital in-patient data, emergency health care data, primary care data, prescription medicines data, cancer registry data, diabetes registry data, cardiovascular disease registry data, formal long-term care data and mortality data.

Source: Authors own calculations based on the results of this study.

Table 4: Key national health dataset availability, maturity and use (1:334)

Half of the countries participating in study 1 reported that within all of their key health care datasets clinical terminology is coded by assigning standard codes using a classification system (Table 2.1). Standard codes ensure that data elements are comparable across datasets and can be analysed for statistical purposes. Across countries, clinical terminology is coded by assigning standard codes using a classification system (Table 2.5). The majority of countries coding clinical terminology within hospital in-patient datasets, cancer registries and mortality datasets were doing so with the aid of health care coding professionals who have been trained to analyse clinical statements and assign standard codes. The use of such professionals was less frequently reported for other datasets. Instead, countries reported that health care professionals, such as nurses and doctors, assign the standard codes. The movement toward health care professionals entering and coding data accompanies the introduction of electronic medical and health record systems. It introduces data quality challenges and requires new approaches to ensure that data records are of high quality, such as health care provider training, data usability evaluations and auditing for data quality.(1:312)

A previous OECD study explored in greater detail the data content standards that were being used for the coding of clinical elements within electronic health record systems (OECD, 2013a). It found considerable variety across countries in the terminology standards used with some countries adopting international terminology standards and others developing national standards. Further there were key data elements with no agreed international terminology standard. Progress toward internationally comparable indicators of health and health care from electronic clinical data will require greater harmonisation toward internationally-agreed terminology standards. (1:324)

Many countries are contending with the use of multiple standards for the same data element. 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. A widely reported barrier to the use of data from electronic health record systems is concerns with the quality of the data, including both a lack of coded data and poorly coded data (3:59)

In spite of using information standards, there are still concerns with the quality of data both for secondary and primary use purposes: The Czech Republic signalled that the national data collected by the Health Ministry (IHIS) is not linked to reimbursement decisions but is provided to IHIS from health care providers. There are no incentives for providers to be rigorous about the quality of the data submitted. The data verification processes at IHIS are routine logic checks similar to those applied by Eurostat. There is no capacity to validate the data by checking data records against original health care records. There is concern that particularly time consuming aspects of the data requested from providers, such as the capturing of co-morbidities, may be of lower quality. Iceland noted that frequently data are not coded in a timely manner and there is a lack of internal data quality audits within health care providers before data are submitted to the national authority. The Netherlands noted that missing data within datasets and the use of different coding systems for the same data elements are barriers to analysis. Norway notes that the lack of structured data and/or use of terminology standards for some data elements are barriers to quality and to analysis of the data. Italy noted that difficulties harmonising data quality across its regions is a barrier to the usability of data at the national level. Spain expressed similar data quality challenges at the national level as well as gaps in the coverage of its national registries. There is also a need to advance data quality assurance standards in Spain. In the United Kingdom, England signalled the lack of quality for certain data elements, such as the capturing of ethnicity within birth data.(1:315)

6.2.2.3 Establishment of standardisation bodies

To move the interoperability agenda forward, many governments have set up specific bodies or agencies to co-ordinate standard-setting and have developed strategies at the national level. Under pressure, vendors and users, as well as international standards organisations, have also started to collaborate more openly in the development and progression of standards. This collaboration has resulted in some level of success. However, even when standards are available, they are often applied in different ways by different institutions. Additional mechanisms are needed to promote their consistent implementation in a manner that achieves interoperability. Besides technological specifications, appropriate incentives, consensus building and other enabling policies all have to be in place.(4:36)

6.2.2.4 Certification

Seven countries reported a **certification process** for software vendors to comply with national standards for clinical terminology and interoperability. (3:22) A variant to this approach, implemented at present only in Canada in a few provinces, has been to establish a certification process that targets vendors' products and services, and includes a number of "usability" requirements such as service levels, technical support responsiveness, financial viability, etc. This process is a targeted effort, within the context of a specific incentive programme to promote EMR/EHR adoption, rather than a broad product certification scheme, as envisaged in the other countries (4:19) Eleven countries report incentives or penalties to encourage health care providers to adopt electronic health record systems conforming to national standards; and to use their EHR system and keep records up-to-date. Six countries reported auditing EHR records for the quality of the clinical information. (P3:22)

EHR product suitability, quality, interoperability, and data portability can often be very difficult to judge, and physicians sometimes find that the product they purchased does not perform as hoped. Among the various instruments available to governments, **certification** helps mitigate risks and increases the confidence of users that the purchased systems will indeed provide required capabilities (e.g. ensuring security and confidentiality) including interoperability with emerging local and national health information infrastructures (Classen et al., 2007). As such, certification of health ICT products can be seen as the first step in helping to ensure that systems deliver the benefits that providers, payers, purchasers and government officials seek and expect. In several OECD countries, health care payers, ranging from governments to the private sector, are now also offering financial incentives for the adoption of certified health ICT systems – for example, for the use of certified EHR and CPOE. The certification of commercial vendor EHR products could, therefore, potentially boost participation in these incentives programmes and simultaneously reduce the risks facing health ICT purchasers, thus acting as a two-stroke catalyst to accelerate adoption. As depicted in Table 4.1 above, four of our six case study countries have formal health care ICT product certification processes. (4:79)

In 2006, the Certification Commission for Healthcare Information Technology (CCHIT) in US certified the first 37 ambulatory – or clinician office-based – electronic health record products as meeting baseline criteria for functionality, security, and interoperability. In 2007, the commission expanded certification to inpatient – or hospital – electronic health record products, which could significantly increase access by both patients and health-care providers to the health information generated during hospital admission or exams. To date, the commission has certified over 200 electronic health record products. (4:82) Inspection of actual vendor products for compliance with CCHIT criteria occurs in a series of three steps. In the first step vendors self-attest by supplying documentation of their system and formally signing an accuracy attestation. The second step involves jury-observed demonstrations of the vendor EHR products, according to the test

scenarios and scripts, running at vendor facility with jurors and proctors observing via simultaneous Web conference/audio conference. Each vendor sets up a test environment that replicates the live environment of its EHR system, and provides appropriate personnel during the demonstration portion of pilot testing to execute all the procedural steps in the published test scripts, as well as to review the elements subjected to technical testing. In the third and last step, independent technical tests of vendor products are performed using off-site laboratories under the oversight of independent testing organisations and using the test scripts outlined above (4:81)

The Health IT Policy Committee in the United States (Certification and Adoption Work Group meeting of 14 July 2009)5 recently noted the issues listed below pertaining to certification of EHRs that are equally reflective of commonly-held certification concerns in other countries:
• The overall goal and purpose of the current certification process is often not properly understood.
• The certification process is excessively detailed. There is too much attention to specific features and functionality.
• Certification addresses the full range of products – open source, selfdeveloped, modular, and other vendor. Home-developed systems and open source developers, often don't understand why they need to go through the expense of detailed certification processes and possibly developing unneeded functionalities for the sole purpose of meeting certification criteria.
• The timeframe and cost involved in certification and re-certification are a concern.
• There is limited evidence that the current certification process has significantly improved interoperability. (4:82)

6.2.3 Care process level interoperability

The development and use of data from electronic health records (EHR) has the potential to support health care innovation and to improve the quality, safety and performance of health care systems. This is because such records can be brought together into an electronic health record system, which contains or virtually links together records from multiple care providers to create a longitudinal view of patients' health care pathways.(1:346)

We are only at the beginning of understanding how new technologies e.g. for remote monitoring including medical devices and apps could contribute to understanding how dynamics in health conditions, health behaviours and exposures to environmental harms impact upon our health and the safety, effectiveness and efficiency of health care treatments. Developing this understanding would require linking or integrating monitoring data with data about care pathways and outcomes. (1:343)

Pathways of care involve understanding health care from the patient's perspective which is the receipt of services, often from a set of providers and involving sets of therapies that have immediate and long-term consequences. Patients journey from diagnosis in primary care to specialist care to emergency rooms to hospital stays and to long-term care services and back and forth among these services and experience improvements and deteriorations in their health during the journey and afterward. The datasets included in this study cover the key health care services provided to patients: hospital in-patient services; community health services including primary health care, emergency health care and formal long-term care (such as nursing homes and home care services). The use of prescription medicines is a key part of the health care services offered to patients that are delivered in hospital, in other care settings and in the community to be used at home. They are both tremendously useful and highly risky products and understanding benefits and risks is essential to keeping patients healthy and safe. Thus these data are a key component of health care pathways and outcomes.(1:344)

Understanding pathways requires linking datasets at the patient level, as current health data are usually collected in silos. As a result, key datasets about elements of the health care pathway must have sufficient detail to enable valid and reliable dataset linkages. The development and use of data from electronic health records (EHRs) has the potential to enable a quantum leap in health care quality and performance assessment because such records can be brought together into an electronic health record system that captures patients' health care pathways and outcomes and, from which, data can be extracted.(1:341)

Countries provided examples of the purpose of the regular data linkages they are undertaking. Key reasons include to develop health care quality and system performance indicators including OECD quality indicators; to measure the co-ordination of care and health care pathways and outcomes; for estimates of compliance to national care quality guidelines; for indicators of health care utilisation and its cost; for measures of disease prevalence; and to measure health and health care use by socio-economic status.(1:347) High-value data about health care pathways and outcomes also support discovery and innovation (1:342)

Ten countries reported having 70% or more of the key national health and care datasets necessary for understanding health care pathways and outcomes. The national personal health datasets reported by countries tend to have very high coverage of targeted populations; rely upon automatic data extraction from electronic clinical and administrative records; and include the use of standard codes for clinical terminology. (1:321)

Countries provided examples of the purpose of the regular data linkages they are undertaking. Key reasons include to develop health care quality and system performance indicators including OECD quality indicators; to measure the co-ordination of care and health care pathways and outcomes; for estimates of compliance to national care quality guidelines; for indicators of health care utilisation and its cost; for measures of disease prevalence; and to measure health and health care use by socio-economic status.(1:348)

Several countries signalled a lack of a legal or regulatory obligation for health care providers, such as physicians and hospitals, to contribute to the development of statistics and research to monitor and improve health and health care pathways. A particular challenge involves the extraction and sharing of data from clinical patient records for statistical purposes. Some countries report legal and policy constraints to extracting and sharing data from electronic clinical record systems for national datasets or projects. In other countries there is no distinction made in law regarding the source of personal health data and data may be drawn from electronic patient record systems for statistical and research purposes, subject to the same rules as those applying to any other sources of personal health data, such as administrative records (1:354)

6.2.4 Information interoperability

The information-level interoperability has been discussed in chapter 4.4.4.2.

6.2.5 Applications –level interoperability

Even when standards are available, they are often applied in different ways by different institutions. Conversion to a new standard-based technology comes at a cost – and for many organisations, it is cheaper to maintain the status quo. We repeatedly heard from national officials that uniform standards have still not been implemented, and that organisations continue to tailor standards to their immediate needs. Despite the aforementioned recent efforts by HL7 and others to enhance and provide more clarity as well as implementation guidance for their

standards, there is no assurance that this information will be conveyed reliably across different vendor systems or enterprises. Given these problems along with the changes in the marketplace and the proliferation of proprietary ICT tools, the transition to interoperability continues to be a challenge (Goldsmith et al., 2003).(4:54)

The MAeHC experience with vendors has been that stipulation of standards and specifications is not enough. Achieving interoperability of health information technology solutions requires detailed negotiations between the vendors involved. This must also be coupled with a highly developed community and practice support organisation to provide the overarching leadership from start to finish which is essential to enabling successful EHR deployment in physician practices. (4:72)

US officials from the ONC have recently noted that many certified EHRs are neither user-friendly nor designed to meet ARRA's ambitious goal of improving quality and efficiency in the health care system (Blumenthal, 2009). This last point highlights a specific inherent weakness common in most countries' product certification process, in that it certifies the product (i.e. EHR, CPOE, etc.) and the specifications and functionalities required, but fails to address how the product will be used to improve performance by clinicians. Actual system implementations can vary considerably from one organisation/ product to another; all certification can ensure is a baseline of core functionalities and specifications that could be used to achieve interoperability. For this reason, a few countries such as Canada, as described below, have chosen to establish a certification process that targets the vendor, and includes a number of "usability" requirements such as service levels, technical support responsiveness, financial viability, etc. On 14 August 2009, the US HIT Policy Committee introduced several important decisions regarding the certification process to address a number of the issues listed above, including expansion of the certification process to improve its objectivity and transparency, and a proposed short-term certification transition plan.(4:83)

Like the certification process, vendor conformance usability requirements (VCUR) define minimum levels of mandated functionality for provider systems, as well as describing technical, interoperability, security, privacy and other requirements. In Canada, the only case study country currently setting VCURs, the process is a targeted effort within the context of a specific health ICT incentive programme rather than a broad product certification scheme, as envisaged in the other countries. The functional areas currently being tested include; billing, scheduling, EMR, workflow, ergonomics, and clinical decision support. Like the certification process, vendor conformance usability requirements (VCUR) define minimum levels of mandated functionality for provider systems, as well as describing technical, interoperability, security, privacy and other requirements. In Canada, the only case study country currently setting VCURs, the process is a targeted effort within the context of a specific health ICT incentive programme rather than a broad product certification scheme, as envisaged in the other countries (4:84)

6.2.6 International collaboration in interoperability

Study (1) reveals several areas where international collaboration is needed, of which one of them is to ensure that there are sufficient agreed international standards for data coding and interoperability (P1:290)

Under pressure, vendors and users as well as international standards organisations have started to collaborate more openly in the development and progression of standards. This collaboration has resulted in some level of success. The open standards of DICOM for digital images and HL7 for clinical messaging are slowly becoming universally available, and were developed through a

voluntary industry and user-driven process. In both cases, health professionals and technology manufacturers collaborated in developing the common formats and protocols for sharing clinical information.(4:90)

Many governments have set up specific bodies or agencies to co-ordinate standards-adoption activities and develop strategies at the national level. In Europe, the European Commission (European e-Health Action Plan, April 2004) has provided a roadmap for the development of interoperable e-health solutions in and across member states. The plan also calls for the creation of interoperable e-health solutions and a European network of centres of reference to promote co-operation across medical institutions. Interoperability issues are high on the agenda of most e-health strategies of European Union countries, and have been identified as a priority area for action. In 2008, follow-up recommendations related to cross-border exchange of information in the EC detailed specific principles necessary for interoperability to be achieved by the end of 2015. (4:71)

6.3 Cross-border sharing of health data

Study 1 depicted OECD guidelines for protection of privacy and the transborder flow of personal data (table 5) (1:303)

The OECD guidelines for the protection of privacy and the transborder flow of personal data outline eight guiding principles for national application:

1. Collection limitation principle	There should be limits to the collection of personal data and any such data should be obtained by lawful and fair means and, where appropriate, with the knowledge or consent of the data subject.
2. Data quality principle	Personal data should be relevant to the purposes for which they are to be used and, to the extent necessary for those purposes, should be accurate, complete and kept up-to-date.
3. Purpose specification principle	The purposes for which personal data are collected should be specified not later than at the time of data collection and the subsequent use limited to the fulfillment of those purposes or such others as are not incompatible with those purposes and as are specified on each occasion of change of purpose.
4. Use limitation principle	Personal data should not be disclosed, made available or otherwise used for purposes other than those specified in accordance with Paragraph 9 except a) With the consent of the data subject; or b) By the authority of law.
5. Security safeguards principle	Personal data should be protected by reasonable security safeguards against such risks as loss or unauthorised access, destruction, use, modification or disclosure of data.
6. Openness principle	There should be a general policy of openness about developments, practices and policies with respect to personal data. Means should be readily available of establishing the existence and nature of personal data, and the main purposes of their use, as well as the identity and usual residence of the data controller.
7. Individual participation principle	An individual should have the right: a) To obtain from a data controller, or otherwise, confirmation of whether or not the data controller has data relating to him; b) To have communicated to him, data relating to him within a reasonable time; at a charge, if any, that is not excessive; in a reasonable manner; and in a form that is readily intelligible to them; c) To be given reasons if a request made under subparagraphs(a) and (b) is denied, and to be able to challenge such denial; and d) To challenge data relating to them and, if the challenge is successful to have the data erased, rectified, completed or amended.
8. Accountability principle	A data controller should be accountable for complying with measures which give effect to the principles stated above.

Source: OECD (2009), *OECD Policies for Information Security and Privacy*. Principles re-confirmed in OECD (2013), *The*

Table 5: Guiding principles fort he protection of privacy and the transborder flow of personal data

In the 2013 OECD country survey, respondents were asked about a set of key data accessibility factors that are directly linked to legislative frameworks and their interpretation in practice. These factors include whether or not identifiable national personal health data are ever shared among data custodians or government entities and whether personal health data, after de-identification, can be approved for access by applicants from different sectors of society and by foreign applicants. (1:340).

Five countries reported that none of the key national health datasets is ever shared in an identifiable format with another data custodian or government entity. As is explored in more detail in other chapters of this report, countries that prohibit the sharing of identifiable data among government authorities may still be able to develop data about health care pathways and outcomes. They do so either because many key datasets are in the custody of
a single organisation (see Chapter 2) or, alternatively, because they have good co-operation among different government entities, and each entity agrees to encrypt identifying variables using the same algorithm, enabling the linkage of de-identified data (see Chapter 7). Virtually all countries reported that analysts from a government authority could apply for and be approved access to the majority of key national de-identified micro datasets. A micro dataset contains records for patients or persons. Only Italy restricts government authorities from accessing de-identified microdata for the majority of national datasets. (1:339)

According to study 1, Some countries make no distinction between foreign and domestic applicants for secondary data use, subjecting both to the same set of rules. Nonetheless, many countries are reticent to approve foreign applications for access to data, due to the inability to impose sanctions on a foreign entity for non-compliance with legal requirements or with the requirements within their data sharing agreement. Some countries will not consider any foreign applications; some will consider only applications for access to de-identified personal health data; while others will consider the approval of the sharing of identifiable personal health data if there is a strong justification for the project. International collaboration is essential for information about best practices and lessons learned in health data governance to circulate widely; and to support movement toward common best practices so that multi-country statistical and research projects are feasible. (1:274)

Similar to Europe, Israel will consider foreign applicants from countries within the European Union or whose data protection legislations are similar to those of the European Union. New Zealand will also consider foreign applications for access to data where the country's privacy legislation offers equivalent protections to that of New Zealand. Further, New Zealand shared two examples where it was necessary to arrange for the sharing of identifiable personal health data across borders. First, there was a need for New Zealand data holders to be able to access cloud computing services offered by service providers in Australia and vice versa. To enable the sharing of cloud computing service providers for the processing of identifiable personal health data, New Zealand and Australia developed cloud computing guidelines which impose the same requirements for data security and protection on organisations in both countries. Second, there has been the need to share identifiable data for cancer research, as there is high population mobility between Australia and New Zealand, as well as cross-border care seeking. For such research to be approved there must be significant benefits of the research results for New

Zealand and the requesting researcher must have the informed consent of the data subjects. (1:293)

In the United States, there is no distinction under HIPAA for foreign entities requesting access to data. Foreign researchers can apply for and receive access to identifiable microdata. Such a disclosure requires the approval of a research ethics board as it would for any domestic applicant. Disclosures may, however, be prohibited by policy. In the United States, in the past, a foreigner could apply for access to de-identified microdata within the NCHS Andre secure remote data access system. However, this practice ended when the Confidential Information Protection and Statistical Efficiency Act (CIPSEA) entered into force in 2011. This law applies to all statistical agencies and statistical units at the federal level and it requires them to supervise and control the use of the data they hold. The interpretation of the law was that access to data by foreigners via Andre might not constitute sufficient supervision and control. Foreign applicants remain welcome to follow the same approval process as domestic applicants, but they can only be granted access to data within the Research Data Centres. Similarly, the AHRQ also offers foreign applicants access to de-identified microdata within its facility only. (1:293)

In Canada, disclosure of de-identified health data is subject to any applicable jurisdictional legislative requirements under which the data were collected originally. CIHI may disclose de-identified data to recipients located outside of Canada except where prohibited by law or by agreement. All disclosures must be reviewed internally by CIHI and approved by CIHI's President and CEO. In some cases, approval from the appropriate Ministry of Health may also be required. Given the additional risk associated with providing data outside the country, it may be necessary to provide further data treatment to reduce re-identification risk, such as less geographic level. The data disclosure agreement and associated data security obligations would be the same as for a domestic applicant. (1:293)

The principle in Korea is to be restrictive on the approval of access to de-identified data from foreign applicants. Data related to the medical services received in Korea is viewed as too sensitive to be shared outside of the country. However, it may be possible to approve the sharing of a sample of the population. In general, the data would only be shared with a foreign government or international organisation when required by treaty or another international agreement. (1:293)

Legislation in Singapore protects patients in Singapore. If data subjects have provided consent, then it is clear that data sharing with a foreign entity could be approved. The concern is how a data breach in a foreign country would be addressed. In cases where there is not consent of data subjects, it may be possible to share anonymised data, but the concern is how the terms of the data sharing agreement with a foreign entity could be enforced. This is not a clearly defined area and decisions on project approval involving foreign entities is determined on a case by case basis and depends on the risk of re-identification and the protections of the security of the data that would be in place. (1:293)

Title	Description	Participating countries	To learn more
The Farr Institute at the Centre for Improvement in Population Health through E-records Research (CIPHER)	To promote research using data from electronic health records and the linkage and analysis of large health-related datasets including social, economic and spatial data; and to build multi-disciplinary capacity in e-health information research. The project is developing collaborations to link previously isolated silos of expertise (observational, interventional, biomedical and social science); improving knowledge exchange between academic, practitioner and policy leads; and liberating information trapped in data islands. The project aims to enable routine health care data to be maximised by enabling research on the full UK population and robust methods to link such data to UK cohorts, surveys and non-health administrative data including embedding cohorts, trials and survey data within this total population structure. The project is to provide the data, methods and skills to enhance observational and interventional research capacity and efficiency, support policy decisions, and quantify the impact of investment in scientific research on population health and wellbeing. Funding was provided from a consortium of 10 UK Government and Charity Funders led by Medical Research Council (MRC).	England, Scotland, Wales	http://www.swansea.ac.uk/medicine/research/researchthemes/patientpopulationhealthandinformatics/ehealth-and-informatics-research/thefarrinstitutecipher/
European Patients - Smart open Services (epSOS)	A large-scale pilot project on cross-border sharing of personal health data from electronic clinical records, including the sharing of patient summaries and e-prescriptions among selected facilities and professionals within the EU. All participants have agreed to a model for data sharing. The project received funding support from the ICT Policy Support Programme, as part of the Competitiveness and Framework Programme of the European Commission.	Project grew to include 25 European countries	http://www.epsos.eu/
Pharmaco-epidemiological Research on Outcomes of Therapeutics by a European Consortium (PROTECT)	To monitor the benefit-risk of medicines in Europe by developing innovative methods to enhance early detection and assessment of adverse drug reactions from different data sources (clinical trials, spontaneous reporting and observational studies) and to enable the integration and presentation of data on benefits and risks. PROTECT is supported by the Innovative Medicines Initiative.	European countries	http://www.imi-protect.eu/objectives.shtml

Table 6: Projects building platforms for internationally comparative statistics and research from data linkages and extraction of data from electronic clinical records (1:369)

A new initiative supporting multi-country data sharing is presented in study 4 – the Farr Institute, United Kingdom (1:375)

6.4 Benchmarking - Monitoring & Assessment of Implementation and impacts

A review of strategic plans and documents with respect to the introduction and dissemination of ICTs across OECD countries further highlights areas where countries may find it useful to share information to monitor progress by ways of international comparisons. These are:

- Adoption and use of electronic health records and related applications;
- Rate of health information exchange;
- Privacy and security measures;
- Adoption and use of standards for interoperability;
- Adoption of organisational change management initiatives;
- Secondary use of data for monitoring public health (4:93)

6.4.1 Adoption and use of electronic health records and related applications

As countries develop and implement their e-health strategies, they will need to monitor progress to ensure their efforts are effective. In 2007, the OECD undertook a study to identify: (1) information needs and the policy objectives that underlie national benchmarking activities; and (2) areas for international action and future research efforts. The study concluded that available national and international data on health ICTs are rarely comparable, due to inconsistent definitions (e.g., what constitutes an EHR differs across countries) as well as statistical reasons (e.g., different sampling techniques). As a result, it is difficult to draw conclusions on ICT adoption, use, or impact on care within and across countries. It is similarly challenging for

countries to evaluate the outcomes of their policies and identify practices from which they could learn. (5:7)

Despite the promise they hold out, implementing ICTs in clinical care has proven to be a difficult undertaking. More than a decade of efforts provide a picture of significant public investments, notable successes and some highly publicised costly delays and failures. This is accompanied by a failure to achieve widespread understanding of the benefits of electronic record keeping and information exchange. With consistent cross-country information on these issues largely absent, the OECD has used lessons learned from case studies in six OECD countries (Australia, Canada, the Netherlands, Spain, Sweden, and the United States) to identify the opportunities offered by ICTs and to analyse under what conditions these technologies are most likely to result in efficiency and quality-of-care improvements. (4:2)

Study 4 highlights an absence, in general, of independent, robust monitoring and evaluation of programmes and projects. While most of the case studies had included some sort of formal evaluation to justify initial budgets, few had conducted a formal post-implementation evaluation to determine the actual payoff from the adoption and use of ICTs. (4:23)

Twenty countries participating in this study 3 (2013) 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 HER 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.(3:286)

Table D.11. **Use of electronic medical and patient records by physicians and hospitals**

	Primary care physician offices			Medical specialist physician offices			Hospitals				
	Capture patient diagnosis and treatment electronically	Proportion with electronic data capture	Share some information about patients electronically	Capture patient diagnosis and treatment electronically	Proportion with electronic data capture	Share some information about patients electronically	Capture data on in-patient diagnosis and treatment electronically	Proportion with electronic data capture	Capture emergency room patient diagnosis and treatment electronically	Proportion with electronic data capture	Share some information about patients electronically
Austria	Yes	> 80%	Yes	Yes	> 90%	Yes	Yes	100%	Yes	n.a.	Yes
Belgium	Yes	70%	Yes	Yes	80%	Yes	Yes	75%	Yes	n.a.	Yes
Canada	Yes	41.3%*	Yes	Yes	36.2%*	Yes	Yes	n.a.	Yes	n.a.	Yes
Denmark	Yes	51%	Yes	Yes	10%	Yes	Yes	100%	Yes	100%	Yes
Estonia	Yes	98%	Yes	Yes	50%	Yes	Yes	100%	Yes	n.a.	Yes
Finland	Yes	100%	Yes	Yes	100%	Yes	Yes	100%	Yes	100%	Yes
France	Yes	n.a.	Yes	Yes	n.a.	Yes	Yes	n.a.	Yes	n.a.	Yes
Germany	Yes	> 80%	Yes	Yes	> 80%	Yes	Yes	> 90%	Yes	n.a.	Yes
Iceland	Yes	100%	Yes	Yes	> 60%	Yes	Yes	100%	Yes	100%	Yes
Indonesia	Yes	≈ 20%	Yes	Yes	n.a.	n.a.	Yes	n.a.	Yes	n.a.	Yes
Israel	Yes	100%	Yes	Yes	≈ 95%	Yes	Yes	100%	Yes	80%	Yes
Japan	Yes	15.2%**	Yes	Yes	15.2%**	Yes	Yes	14.2%	Yes	n.a.	Yes
Korea	Yes	63.5%	No	Yes	52-66%***	Yes	Yes	52-66%***	Yes	52-66%***	Yes
Mexico	Yes	≈ 15%	Yes	Yes	n.a.	No	Yes	≈ 30%	Yes	n.a.	Yes
Netherlands	Yes	100%	Yes	Yes	100%	Yes	Yes	100%	Yes	100%	Yes
Poland	Yes	≈ 15%	Yes	Yes	≈ 10%	Yes	Yes	≈ 5%	Yes	n.a.	No
Portugal	Yes	90%	Yes	Yes	50%	Yes	Yes	70%	Yes	95%	Yes
Singapore	Yes	14%	No	Yes	60%	Yes	Yes	80%	Yes	80%	Yes
Slovak Republic	Yes	n.a.	n.a.	Yes	n.a.	n.a.	Yes	n.a.	Yes	n.a.	No
Slovenia	Yes	90%	Yes	Yes	90%	Yes	Yes	90%	Yes	90%	Yes
Spain	Yes	?90%	Yes	Yes	≈ 25%	Yes	Yes	≈ 70%	Yes	≈ 45%	Yes
Sweden	Yes	100%	Yes	Yes	100%	Yes	Yes	100%	Yes	100%	Yes
Switzerland	Yes	20%	Yes	Yes	n.a.	Yes	Yes	90%	Yes	n.a.	Yes
United Kingdom	Yes	≈ 100%	Yes	Yes	20%[1]	Yes	Yes	100%	Yes	100%	Yes
United States	Yes	57%**	Yes	Yes	57%**	Yes	Yes	18.9%	Yes	n.a.	Yes
Total Yes	25		22	25		22	25		25		23

Note: n.a.: not applicable.

Table 7: Use of electronic medical and patient records by physicians and hospitals (3:285)

In the 2013 report, 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).(3:287)

Between years 2008-2013, OECD prepared a Guide to Measuring ICTs in the Health Sector with the aim to provide a standard reference for statisticians, analysts and policy makers in the field of health Information and Communication Technologies (ICT). The objective is to facilitate cross-country data collection, comparisons and learning on the availability and use of health ICTs.(5:1)

The model survey addresses four categories of broadly defined domains in which ICTs support care delivery:

1. Provider-centric Electronic Records Often referred to as Electronic Medical Records (EMRs), Electronic Health Records (EHRs), or Electronic Patient Records (EPRs), provider-centric electronic records include systems that are used by healthcare professionals to store and manage patient health information and data, and include functionalities that directly support the care delivery process.
2. Patient-centric Electronic Records. Often referred to as Personal Health Records (PHRs), Patient Portals, and other Patient-centric Electronic Records, these systems are typically used by patients and their families to access and manage their health information and organize their health care.
3. Health Information ExchangeHealth Information Exchange (HIE) refers to the process of electronically transferring, or aggregating and enabling access to, patient health information and data across provider organisations. Exchange may take place between different types of entities – for example, e-transfer of patient data between ambulatory care providers or e-transfer of data at the regional level.
4. Telehealth.Telehealth encompasses a broad set of technologies that support care between patients and providers, or among providers, who are not co-located. Telemedicine is often defined as synchronous video-mediated consultations between physicians and patients. However, it may also include applications such as remote home monitoring of patients, tele-ICUs, and teleradiology. (5:8)

Figure xx presents the core content of the model survey on health ICTs availability and use (5:9)

Provider-centric electronic record	Patient-centric electronic record	Health Information Exchange	Tele-health
1. Entry of core patient data (e.g., medication allergies, clinical problem list)	1. Viewing of clinical data (e.g., test results)	1. Secure messaging between professionals	1. Tele-home care/tele-monitoring
2. Decision support (e.g., drug-drug alerts)	2. Supplementation of clinical data (e.g., entering or modifying current medications)	2. Ordering and reporting of medications and lab tests with result receipt	2. Remote consultation
3. Closed-loop medication administration	3. Appointment scheduling	3. Patient referrals	3. Asynchronous communication
4. Clinical documentation	4. Medication renewal		

Table 8: Categories of broadly defined ICT domains

The most recent results on OECD-level Health ICT benchmarking are reported in JAMIA article (http://jamia.oxfordjournals.org/cgi/reprint/ocw111?ijkey=OMS5U99LNXuUyYt&keytype=ref) The study used the most comparable measures available to date integrated into national data collections. Results showed substantial diversity in health ICT availability and use in all domains. The project also identified methodological considerations (e.g.,

structural and health systems issues that can affect measurement) important for future comparisons.. There were some discrepancies in data collected by the EU and by national sources. By identifying variations and describing key contextual factors, benchmarking offers the potential to facilitate cross-national learning and accelerate the progress of individual countries. (Zelmer et al 2016)

6.4.2 Monitoring rate of health information exchange

Five countries of the 25 participating in study 1 reported that none of the key national health datasets is ever shared in an identifiable format with another data custodian or government entity. As is explored in more detail in other chapters of this report, countries that prohibit the sharing of identifiable data among government authorities may still be able to develop data about health care pathways and outcomes. They do so either because many key datasets are in the custody of a single organisation (see Chapter 2) or, alternatively, because they have good co-operation among different government entities, and each entity agrees to encrypt identifying variables using the same algorithm, enabling the linkage of de-identified data (see Chapter 7). Virtually all countries reported that analysts from a government authority could apply for and be approved access to the majority of key national de-identified micro datasets. A micro dataset contains records for patients or persons. Only Italy restricts government authorities from accessing de-identified microdata for the majority of national datasets.(1:339)

	Identifiable data is shared with other data custodian or government entities	Government analysts may be approved access to de-identified data	University and non-profit researchers may be approved access to de-identified data	Health care providers may be approved access to de-identified data	For-profit businesses may be approved access to de-identified data	Foreign government, university or non-profit researchers may be approved access to de-identified data
Canada	75%	88%	88%	88%	75%	63%
Czech Republic	0%	100%	100%	100%	0%	100%
Denmark	78%	89%	89%	89%	78%	56%
Finland	78%	78%	78%	78%	78%	78%
Iceland	0%	100%	100%	100%	100%	100%
Ireland	80%	100%	100%	100%	60%	40%
Israel	67%	100%	33%	50%	0%	0%
Italy	14%	29%	86%	0%	0%	0%
Japan	0%	86%	100%	0%	0%	0%
Korea (Rep. of)	100%	100%	88%	0%	0%	0%
Netherlands	14%	71%	71%	71%	ns	57%
New Zealand	100%	100%	100%	100%	100%	100%
Norway	57%	100%	60%	100%	40%	100%
Singapore	75%	100%	100%	100%	0%	13%
Spain	75%	100%	75%	75%	75%	75%
Sweden	89%	89%	89%	89%	89%	89%
Switzerland	0%	100%	100%	100%	100%	100%
Turkey	0%	100%	0%	0%	0%	0%
United States	29%	100%	100%	100%	100%	100%
UK England	100%	100%	100%	100%	100%	100%
UK Scotland	100%	100%	100%	100%	100%	100%
UK Wales	14%	86%	86%	86%	86%	86%

ns: Not stated.

Source: Author's own calculations based on the results of this study.

Table 9: Proportion of key national personal health datasets meeting six data accessibility factors

6.4.3 Monitoring Privacy and security measures

The term privacy appeared in 725 quotations in the five documents analysed in the first round. Quotations related to privacy and policy priorities have been depicted in chapter 4.1.5 and quotations related to privacy and legislation have been depicted in chapter 4.4.3.2.

Study 3 focused on strengthening health information infrastructure, with a chapter 5 on Protection of privacy in the collection and use of personal health data. This chapter covered variations in risk management lead to differences in OECD country practices, Guiding principles and legislation, Privacy principles in practice – country variation, Multiple data custodianship and data sharing and Data linkage activities and compliance with legislation (3:69) Chapter 2 focused on 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.(3:89) In addition, Aspects of the governance of data linkages and the provision of access to data are discussed in Chapter 6. This include 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.(3:92)

Results of study 3 show that In some countries, there is potential to continue and to expand data linkage studies in the future due to having reached a shared understanding with their data privacy officials of the requirements to respect principles of data privacy. This includes standardised processes for project approval, access to data and data security. There is also potential for data from electronic health record systems to be used for health care quality monitoring over the next five years. This is due to both the number of countries that plan to implement national electronic health record systems and the number of countries that consider it likely that the data from these systems will be used for some aspects of health care quality monitoring.(3:75) Cross-country differences in the application of privacy principles are significant and can be attributed to differences in risk management in the balancing of individual rights to privacy and collective rights to safe and effective health care and to a high performing health system. Many countries report legislative barriers to the use of personal health data, including enabling data linkages and developing databases from electronic health records.(3:77) A principle challenge is the lack of clarity about the interpretation of legislations concerning the protection of data privacy at the national and sub-national levels. This includes the legality of data sharing among public authorities and providing access to data for research. (3:78) The resources required to comply with legislative requirements to enable data use is a secondary problem, as is the cost of developing the technical capacity to undertake the work. (3:79)

A role for the OECD in the coming years is to continue to support countries in reaching the goal of strengthening health information infrastructure so that privacy-respectful uses of data for health, health care quality and health system performance monitoring and research become widespread, regular activities. On-going monitoring of the development of health information infrastructure will help to promote shared learning about advancements (3:80) Another important step will be to support countries in reducing unnecessary obstacles to data use that can arise from differences in legislations regarding the protection of health information privacy and differences in the interpretation of what is necessary and helpful

to assure that patients' privacy rights are respected in the conduct of health monitoring and research. A risk classification of data and data uses, to identify cases of higher risk to patient's information privacy and to associate recommended data privacy protection practices that will enable even very sensitive data to be used for research and monitoring, would support countries in developing privacy-respectful uses of data to improve health, health care quality and health system performance.(3:81)

Study 1 focused on privacy, monitoring and research, with interviews as the main method. This OECD study was undertaken by the OECD HCQI (Health Care Quality Indicators) Expert Group as part of the 2013/14 programme of work of the OECD Health Committee. The OECD Working Party on Security and Privacy in a Digital Economy (SPDE) provided input to the study.(1:387).

A data governance framework with mechanisms and best practices to protect health data privacy at all stages of data development and use is the best way forward to create an environment within which the benefits of safe data use can be realised.(2:19) To support OECD countries in improving data governance frameworks, health ministries and data privacy protection experts in OECD countries collaborated in 2013/14 to pursue this in-depth investigation to understand the current situation, to uncover and document practices, and to identify promising data governance mechanisms that enable privacy-protective monitoring and research. Advice and guidance on all aspects of this study were provided by a multi-disciplinary panel of experts.(1:275)

The results show that while all countries are investing in health data infrastructure, there are significant cross-country differences in data availability and use, with some countries standing out with significant progress and innovative practices enabling privacy-protective data use; and others falling behind with insufficient data and restrictions that limit access to and use of data, even by government itself. Countries that develop a data governance framework that enables privacy-protective data use will not only have the information needed to promote quality, efficiency and performance in their health systems, they will become a more attractive centre for medical research and will have opportunities to build public-private partnerships.(1:410)

After examining the current situation in OECD countries, data governance mechanisms were identified to maximise societal benefits and to minimise societal risks from uses of health data. These mechanisms build forward from existing efforts, such as the OECD Privacy Framework (OECD, 2013) and the European Data Protection Directive (95-46-EC), to begin to address an unmet need for an international consensus about effective practices in the protection of privacy in the use of personal health data, so that we may facilitate greater harmonisation of privacy-protective monitoring and research activities. The mechanisms should assist countries developing governance frameworks and engaging in legislative reforms, including those necessary as the result of the anticipated EU Data Protection Regulation.(1:412)

The study reveals several areas where international collaboration is needed, including support to countries to evaluate which national legal frameworks for the protection of health information privacy provide adequate protections to facilitate multi-country statistical and research projects; review current practices in patient consent and in waivers to consent to reach a common understanding about mechanisms that are privacy protective; review developments in data security risks and threats and mechanisms to address them; and explore mechanisms to engage the public in discussion about data and its governance to ensure that there is good public

awareness of health data, the benefits of its use, its protection, and the rights of data subjects.(1:279)

Country experts provided examples of the guidelines and policies that have been developed to protect data privacy and security.(1:121) Data custodians provided examples of the approaches taken to ensure that current and new staff members remain aware of their data privacy and security protection responsibilities.(1:728) Data custodians provided examples of the approaches taken to ensure that current and new staff members remain aware of their data privacy and security protection responsibilities.(1:803) Country experts provided examples of the features of the physical security of their premises and the IT security of their information systems that help to protect the data they hold.(1:804) Experts in 14 countries indicated that a signed obligation, such as a data sharing agreement or contract, is used to legally bind data recipients to the rules to be followed to protect the privacy and confidentiality of the data for which they have been approved access (Canada, Czech Republic, Denmark, Finland, Iceland, Israel, Korea, Norway, Singapore, Spain, Sweden, Switzerland, United States and United Kingdom).1:736)

Three countries responding to this study noted engaging with external service providers (External data processors and cloud computing services) for assistance with the processing of personal health data (United Kingdom, Spain and New Zealand) to meet the needs as health dataset volumes grow, with the development of data from electronic record systems and the storage of genetic and genomic data.(1:805)

Study 1 reported that Secure research data centres and secure remote data access systems are viable alternatives to transferring identifiable and de-identified personal health data from data custodians to third party data requestors such as other government ministries, university and non-profit researchers, commercial researchers, or to foreign researchers. These secure facilities are very effective at both broadening access to data for approved projects while at the same time reducing the risk that data could become re-identified or otherwise misused. (1:806)

The Advisory Panel of Experts on Health Information Infrastructure identified the following data security and management practices as key elements of privacy-protective data use:
7. Best practices in data security and management should are applied to reduce re-identification and breach risks. Data security and management practices should provide for:
a) Controlling and monitoring physical and IT data security within data custodians and processors.
b) Controlling and monitoring to ensure that access to and use of personal health data within data custodians or processors is performed by staff subject to confidentiality rules/regulations.
c) Limiting data transfers to and from data custodians or processors to secure channels.
d) Requiring legally binding contracts with recipients of personal health data or de-identified person level data from custodians or processors that specify the data confidentially and security requirements to be respected.
e) Ensuring data custodian staff, data processor staff and third-party data recipients of personal health data or de-identified person-level data have mandatory and periodic training on data privacy and security protection through on-line training or other means.
f) Before transferring data, reviewing the physical security and security policies and practices of data recipients and any parties mediating data transfers.
g) Conducting independent and random data security audits of data recipients and any parties mediating data transfers.

h) Following-up with data recipients to verify data destruction requirements and any other end of contract requirements have been met.
i) Offering alternatives to transferring data, such as providing data access within a research data centre or through a secure data portal, or analysing the data within a certified/accredited organisation.
j) Implementing penalties for data misuse by any party, such as contractual, financial or criminal penalties (1:376)

In study 1, countries were asked for their views about progress over the past five years in the use of personal health data to monitor health and health care quality and the outlook for the next five years. Eleven countries indicated that it has become easier or much easier to use personal health data to monitor health and health care quality over the past five years. Reasons for this included both technical improvements to data and data processing; as well as a strengthening of legislative frameworks governing health information privacy and greater clarity about the interpretation of legislation in practice. Sixteen countries are optimistic that they will be able to link datasets to monitor health and health care quality over the next five years and 13 countries indicate that it is likely or very likely that data will be extracted from electronic clinical records for this purpose. This optimism is either because such monitoring is already in place or because of improvements in data infrastructure including data quality, tools for data processing and progress in developing and standardising electronic health record systems.(1: 761)

As was presented in report 1, countries that have developed strong health data governance frameworks provided good examples of how data can be used safely to benefit society (1:807)

The Advisory Panel of Experts on Health Information Infrastructure identified the following practices as key to ensuring that data governance mechanism will remain relevant over time, that include privacy:

- review privacy legislations in OECD countries, compare similarities and differences, and create a list of countries sharing similar and adequate data privacy protection
- review current practices in patient consent and reach agreement on privacy-protective mechanisms to request/waive consent for research and statistics involving large health datasets
- review developments in data security risks and in software and IT processes to assist with risk mitigation
- review approaches to public consultation and public information about data uses, risks and risk mitigations.(1:783)

6.4.4 Monitoring Adoption and use of standards for interoperability

In study 3, 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.(3:288) 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.(3:289)

6.4.5 Monitoring Adoption of organisational change management initiatives

Even if monitoring of organisational change was listed as one of the areas where countries may find it useful to share information to monitor progress by ways of international comparisons, there was only one quotation matching organisational change: implementation of standards and appropriate organisational changes are necessary to facilitate cross-system link-ups. (4:150) There were no references to actual studies on this topic.

6.4.6 Monitoring Secondary use of data for monitoring public health

Health data collected by national governments that can be linked and shared are a valuable resource that can be used safely to improve the health outcomes of patients and the quality and performance of the health care systems that serve them. Data allowing a comprehensive view of health care services permit **uncovering medical errors**, **adverse drug reactions**, **fraud**, **adherence to clinical guidelines**, **effective treatments**, **optimal care paths** and **optimal responders to treatment** (1:271)

Essential to health care quality and performance assessment is the ability to follow patients as they progress through the health care system from primary health care to speciality care to hospitalisations, long-term care, home care, hospice care and death. These data should also provide information about underlying patient characteristics, illnesses, medications, therapies, tests and images. This type of follow-up permits a comprehensive view of health care services provided and the health outcomes of those services; and permits uncovering medical errors, adverse drug reactions, fraud, adherence to clinical guidelines, effective treatments, optimal care paths and optimal responders to treatment. Understanding pathways requires linking datasets at the patient level, as current health data are usually collected in silos. As a result, key datasets about elements of the health care pathway must have sufficient detail to enable valid and reliable dataset linkages. The development and use of data from electronic health records (EHRs) has the potential to enable a quantum leap in health care quality and performance assessment because such records can be brought together into an electronic health record system that captures patients' health care pathways and outcomes and, from which, data can be extracted.(1:292)

The efficient sharing of health information is indispensable for the effective delivery of care. ICTs that ensure the timely and accurate collection and exchange of health data are likely to foster **better care co-ordination**, and the more efficient use of resources. ICTs can also make important fundamental contributions toward improving aspects of **patient safety**. Case studies show that the use of ICTs to increase **compliance with guideline**- or protocol-based care, particularly for the management of highly prevalent chronic diseases such as diabetes or heart failure, which are strongly associated with preventable hospitalisations, provides an opportunity

for significant "quick wins". P 4: improving health sector efficiency - the role of ict.pdf - 4:4 [Findings illustrate the potent..] (14:131-14:455) (Super) Codes: [study findings]

6.4.6.1 Defining health care quality indicators

For ten years, the OECD Health Care Quality Indicators Programme has been developing and reporting indicators of quality and performance across the domains of primary care, patient safety, hospitalisation outcomes and cancer care. This collaborative initiative has resulted in progress in the methodologies for comparable indicators, as well as progress in the development of the underlying data that enable the indicators. As of 2013, however, only one-half of OECD countries were able to report quality indicators requiring dataset linkages, such as mortality within 30 days after hospital admission for AMI or for Ischemic stroke (OECD, 2013b). Only seven countries were able to report on excess mortality from schizophrenia or from bipolar disorder. Within Europe there are collaborative efforts funded by the European Union to advance health system performance and quality through analysis of large-scale databases. A few key examples from the EU seventh framework research programme are EU-ADR, EuroHOPE, and ECHO (1:267)

Health Ministry leadership is necessary to ensure that delivering the data to manage this important sector is at the forefront of government policy and action. Previous OECD work has found a high variability across OECD countries in data availability and use to concerns about and uncertainty about how to protect patient's rights to privacy and to preserve the security of health data when data are shared, linked and analysed (1:272)

6.4.6.2 Monitoring health information assets

The OECD has been surveying countries about their health information assets and the use of these assets for statistics and research since 2011. (1:368) High-value health data supports health care management, policy and innovation. Study 1 reports on progress in national dataset availability since 2011. Highest coverage of the target population are in the key datasets of Denmark, Finland, Sweden and Iceland. Automatic extraction of electronic data is prevalent in 13 countries. Twelve countries reported consistently coding health care data using a terminology standard. There are still concerns with the quality of the data. Six countries use all of their national health care datasets to regularly report about the quality and performance of health care. Finland, Iceland, Singapore, Sweden, the United Kingdom (Scotland and Wales) have the highest proportion of key national health datasets sharing the same unique patient ID number. Finland, Iceland, the United Kingdom (England) and Singapore are regularly linking most of their national health care datasets for statistics and research. There has been little change in data linkage activities since 2011. National projects advancing high-value data to promote health and improve health care are depicted in study 4. (1:291)

In the 2013 OECD country survey, participating countries were asked about the availability, characteristics and uses of the following 14 key sources of national personal health data. Ten countries reported 70% or more of these datasets are available at the national level: Canada, Denmark, Finland, Iceland, Japan, Korea, Norway, Singapore, Sweden, and Turkey (1:296):

- hospital in-patient data,
- mental hospital in-patient data,
- emergency health care data,
- primary care data,
- prescription medicines data,
- cancer registry data,

• diabetes registry data,
• cardiovascular disease registry data,
• mortality data,
• formal long-term care data,
• patient-reported health outcomes data,
• patient experiences survey data,
• population health survey data and
• population census or registry data.

These datasets were identified because of their potential to provide high information value. In particular, they support both the potential to understand pathways of care and outcomes for all people and for groups of people with different characteristics. They are the essential building blocks for understanding what works? For whom? When? And why? Pathways of care involve understanding health care from the patient's perspective which is the receipt of services, often from a set of providers and involving sets of therapies that have immediate and long-term consequences. Patients journey from diagnosis in primary care to specialist care to emergency rooms to hospital stays and to long-term care services and back and forth among these services and experience improvements and deteriorations in their health during the journey and afterward. The datasets included in this study cover the key health care services provided to patients: hospital in-patient services; community health services including primary health care, emergency health care and formal long-term care (such as nursing homes and home care services). The use of prescription medicines is a key part of the health care services offered to patients that are delivered in hospital, in other care settings and in the community to be used at home. They are both tremendously useful and highly risky products and understanding benefits and risks is essential to keeping patients healthy and safe. Thus these data are a key component of health care pathways and outcomes. (1:295)

srengthening of data governance mechanisms including legislative reforms to protect personal health data (Israel); clarity about data governance including the definition of de-identified data and the rules for data sharing (New Zealand, United Kingdom); and the introduction of a trusted third party to conduct data linkages and de-identify data (1:871)

There has been some progress in dataset availability among the twelve countries that participated in the OECD HCQI Information Infrastructure surveys in both 2011 and 2013. Highest coverage of the target population is in the key datasets of Denmark, Finland, Sweden and Iceland. Automatic extraction of electronic data is prevalent in 13 countries. Twelve countries reported consistently coding health care data using a terminology standard. Retention periods for personal health data vary greatly. Concerns with the quality of the data have been dealt with in chapter 4.5.2. Six countries use all of their national health care datasets to regularly report about the quality and performance of health care. Finland, Iceland, Singapore, Sweden, the United Kingdom (Scotland and Wales) have the highest proportion of key national health datasets sharing the same unique patient ID number. Finland, Iceland, the United Kingdom (England) and Singapore are regularly linking most of their national health care datasets for statistics and research. There have been little change in data linkage activities since 2011. (1:294)

Countries provided a number of examples of obstacles to data sharing among the national authorities in the custody of key datasets that are having a negative impact on the development of statistics and the conduct of research across the pathway of health care. The challenges faced involve differences in legal requirements and data sharing policies among national dataset custodians. (1:221)

6.5 Other study results

6.5.1 Monitoring National EHR data quality and usability

Most countries who have already implemented all or part of their national EHR are concerned with the quality of the data within the records. Noted obstacles to quality include the complexity of the EHR system, which may make it difficult to use; the complexity of the structured data elements and terminology standards, that may be a barrier to their use or to their correct use; and remaining reluctance or scepticism among health care providers to use the system or to appreciate the benefits of using the system. Strategies to address these issues include financial incentives to implement and use records and efforts to work with vendors to increase the user-friendliness of the system (Table D.18). Very few countries, however, are auditing the clinical content of electronic records for quality yet. Audit processes for electronic billing information are more common. Six countries reported auditing EHR records for the quality of the clinical information. (P3:22)

Study 4 found concerns with data quality: The Czech Republic signalled that the national data collected by the Health Ministry (IHIS) is not linked to reimbursement decisions but is provided to IHIS from health care providers. There are no incentives for providers to be rigorous about the quality of the data submitted. The data verification processes at IHIS are routine logic checks similar to those applied by Eurostat. There is no capacity to validate the data by checking data records against original health care records. There is concern that particularly time consuming aspects of the data requested from providers, such as the capturing of co-morbidities, may be of lower quality. Iceland noted that frequently data are not coded in a timely manner and there is a lack of internal data quality audits within health care providers before data are submitted to the national authority. The Netherlands noted that missing data within datasets and the use of different coding systems for the same data elements are barriers to analysis. Norway notes that the lack of structured data and/or use of terminology standards for some data elements are barriers to quality and to analysis of the data. Italy noted that difficulties harmonising data quality across its regions is a barrier to the usability of data at the national level. Spain expressed similar data quality challenges at the national level as well as gaps in the coverage of its national registries. There is also a need to advance data quality assurance standards in Spain. In the United Kingdom, England signalled the lack of quality for certain data elements, such as the capturing of ethnicity within birth data.(1:297)

Processes to evaluate the usability of data from electronic health records for statistical purposes are more widely reported. For the most part, these efforts occur, hand in hand, with database creation and analysis of electronic health records (3:58) Some countries are setting vendor conformance usability requirements (see chapter 4.4.6). The studies included in this report contain no OECD results on wide-scale monitoring of usability of the systems.

6.5.2 Measuring impacts of ICTs

The development of benchmark measures in health ICTs has been guided by three overarching principles. First, measures needed to respond to policy and information needs of countries along a continuum, starting from ICT availability, moving towards effective use, and ending with measuring outcomes and impact on population health. A continuum-based approach has the advantage of accommodating countries that are at different levels of maturity and progress towards achieving their ehealth goals. For example, advanced countries are unlikely to devote substantial resources to collecting data on availability of ICTs if their policy needs are focused on effective use and better outcomes. Having a continuum approach allows these countries to participate in the broader process.(5:10)

According to study 1, Measuring the impacts of ICTs is difficult for a number of reasons. ICT implementation may have effects that are multidimensional and often uncertain in their reach and scope, and difficult to control. In addition, the realisation of benefits from ICT implementation strongly depends on contextual conditions. For example, moving to an EHR in its fullest form is not just a technical innovation; it is a cultural transformation. Change management is vital for successful uptake, and failure to build in processes for effecting the necessary organisational transformations will reduce both uptake and impact. Coupled with this, are inherent difficulties in defining what constitutes health ICTs, the extent of its use and adoption, and the fact that in many cases health institutions may use both ICT and more traditional practices simultaneously. Benefits of new ICT systems may, therefore, only become apparent after working practices have changed or adapted to take advantage of the new resource and this process could take several months or years, presenting a particular problem for those looking to evaluate projects. The challenges described above place health ICT investments in a space that is quite different from other capital investments in the health sector, for example a hospital building or medical equipment. But health ICT projects are still often evaluated using traditional appraisal techniques, limiting evaluation to the objectives of sound financial management. However, providing
decision makers with direct cost-analysis cash-flow projections, financial figures etc., is not enough, since the ultimate strategic objective is to improve the efficiency and quality of clinical care through health ICTs. These methodological difficulties are further exacerbated by data limitations, definitional problems and the lack of appropriate sets of indicators on adoption and use of ICTs which can be compared over time, within and across countries. For many of the hypothesized modes by which ICTs might effect efficiency in health care systems, there is little or no available data which would allow measurement. Despite a plethora of anecdotal information,
the hard evidence available today on the impact of health ICTs is, therefore, inconsistent, which makes it difficult to synthesise and interpret. The scale of most ICT projects and the huge sums of taxpayers' money that have been and are being spent on them, make it crucial for governments
to address the issues of benchmarking and of accountability so that lessons can be learned. Failure to collect the data necessary to evaluate the impact of ICTs is one of the core challenges to achieving widespread adoption of high-performing ICT initiatives.(4:21)

Findings of study (1) illustrate the potential benefits that can result from ICT implementation according to four broad, inter-related categories of objectives (4:4) Findings of study 1 cast no doubt on the potential ability of countries to make major progress toward key policy goals such as improving access to care in remote areas or better care co-ordination for chronic diseases through implementing ICTs. In particular, they prove that cost-effective solutions for remote and rural areas are possible. The Northern Health Authority in British Columbia was able, for example, to provide a secure, high-speed wireless communications network for over 97% of the region's rural private physician's offices through a CAD 1.2 million (~USD 1.14 million) grant from the federal Primary Health Care Transition Fund. In Australia, the Great Southern "Managed Health Network" developed a secure web-based electronic messaging system that is being now rolled out in the most remote areas of the region with start-up funding of AUD 1.8 million (~USD 1.3 million) from the government's Managed Health Network Grant programme. (4:25)

6.5.3 Reducing operating costs of clinical services.

Existing evidence is not sufficient to clearly define who pays for and who benefits from health information technology implementation. Case studies show that Health ICTs can 1) increase the safety of medical care 2) improve workflows by facilitating tasks such as medication reconciliation, and by bringing DSS to the point of care 3) reduce operating costs of clinical services 4) reduce administrative costs 5) achieve "transformation" of care by effectively providing means to implement changes that are otherwise impossible, improving access to care (telemedicine), improving cronic care, multiple service delivery and care coordination, and improving feedback on quality of care. The MAeHC has developed standardised and nationally-recognised metrics using data directly from HIEs that can be used to monitor quality and cost of care, providing a shorter feedback loop for clinicians who can adjust their working practice as appropriate (4:4)

Specific components or functionalities of EHRs (e.g. ePrescription) are likely to have more positive effects on efficiency than others and depending on context. The use of ICTs to increase compliance with guideline-based care, particularly for chronic diseases such as diabetes or heart failure, associated with preventable hospitalisations, provides an opportunity for significant "quick wins".(4:219) (PACS) are considered an indispensable part of the drive towards a fully functional EHR and for the delivery of high-standard remote care through telemedicine, as well as to improve the processing time (or overall "throughput") of medical images and a cost-effective electronic alternative to conventional methods of storing images(4:4)

6.5.4 Reducing administrative costs.

Administrative processes associated with health care such as billing represent a prime opportunity for savings. For example, the health care provider Baystate Health was able to save more than USD 1.5 million through lowered transaction fees in less than three years. P 4: improving health sector efficiency - the role of ict.pdf - 4:4 [Findings illustrate the potent..] (14:131-14:455) (Super) Codes: [study findings]

6.5.5 Enabling entirely new modes of care.

The case studies in this report provide good evidence that governments have significantly leveraged this potential while pursuing three broad health reform agendas:

1) Primary care renewal: in the six countries covered by the case studies considered here, ICTs are central to efforts to renew primary care, generally by targeting three areas of considerable need: improving chronic care, encouraging broad-based general practice or multipurpose service delivery and better care co-ordination.
2) Improved access to care: ICTs, specifically telemedicine combined with PACS, are also used to great effect in areas with large rural or remote populations to reduce the impact of the shortage of physicians and improve access to care
3) Improved quality of care measurement and performance monitoring: all six countries are aiming to use ICTs also to enhance their health information systems. Electronic data collection and processing can provide data in an accessible form that facilitates reporting on different quality metrics, benchmarking and identification of quality improvement opportunities.(4:213)

6.5.6 Prerequisites for successful implementation and adoption of the ICTs

Findings of study (1) also illustrate the three prerequisites for successful implementation and widespread adoption of the ICTs:

1) *Alignment of incentives and fair allocation of benefits and costs*: since the costs and benefits associated with adopting new technologies are not shared equitably among stakeholders, investments which are cost-effective from the point of view of the

system as a whole are not automatically going to be undertaken. Reducing the financial barriers, shifting or sharing the financial risk, and providing much more robust evidence on the advantages of health ICT can, therefore, be expected to accelerate its adoption P 4: improving health sector efficiency - the role of ict.pdf - 4:17 [Reducing the financial barrier..] (19:1656-19:1858) (Super) Codes:[Incentives]

2) *Commonly defined and consistently implemented standards*: While health care organisations have access to an ever-increasing number of information technology products, "linkages" remain a serious problem. Inconsistent medical terminology, clinical records and data storage, as well as a multiplicity of schemes introduced to facilitate interconnection and communication between specific ICT systems remain challenges. EHR systems must be interoperable, clinical information must still be meaningful and easy to decipher once transferred, whether between systems or between versions of the same software. It must also be gathered consistently if it is to permit effective secondary analysis of health data. Electronic capture of data through EHRs can facilitate clinical research, as well as improve evidence-based care delivery. The development of standards to enable interoperability continues to be a political and logistical challenge and a barrier to seamless exchange of information. The problem of lack of interoperability is, however, not one that will be easily solved by the natural operation of market forces. Nor can it be solved by the intervention of health authorities alone: joint industry and government commitment is necessary. P 4: improving health sector efficiency - the role of ict.pdf - 4:18 [While health care organisation..] (21:198-21:1195) (Super)Codes: [Incentives] [Standardisation]
3) Ensuring privacy and confidentiality: because of the sensitivity of health information, and the generalised uncertainty on how existing legal frameworks apply to health ICT systems, privacy concerns constitute one of the most difficult barriers to overcome if widespread implementation of ICTs is to be achieved.

7 OECD view on exchange of knowledge, Global Cooperation& Positioning – collaboration with EU, WHO, Common fund, HIMSS, Standardisation organisations

7.1 WHO collaboration

WHO was mentioned in the studies in five different contexts:

1) As source for coding systems, e.g. Clinical terminology classification system: Standard sets of terms, names and codes to be used for health care coding. For example, the WHO ICD (International Classification of Diseases) is often used for diagnosis coding; the WHO ATC (Anatomical Therapeutical Chemical Classification System) is often used for coding medicines; and SNOMED-CT (Systemised Nomenclature of Medicine – Clinical Terms) provides a broad set of standardised clinical terms for software applications and is increasingly used in electronic clinical records.(1:308)
2) As source of term definitions: Teledermatology: The field of telemedicine involving the use of ICT to transmit medical information concerning skin conditions and tumours of the skin for the purpose of interpretation and/or consultation. Source: WHO (5:52)
3) As source of glossaries in the studies to set survey questions in context: Countries should consider supplementing the Glossary, where needed, in order to ensure that respondents understand the questions in their local context. (5:56)
4) As a member of Expert groups: An OECD Expert Group representing 30 countries (including India, Brazil, and Egypt, as well as the European Commission (EC), the World

Health Organisation (WHO) and BIAC (Business and Industry Advisory Committee) and four expert sub-groups or Task Forces, chaired respectively by J. Zelmer (Canada), P. Hämäläinen (Finland), M. Sprenger (the Netherlands), J. Thorpe (United Kingdom) brought a range of relevant expertise and country representation to this initiative. (5:11)

5) As setter of policy goals: Stroke is one of the leading causes of death and disability in Europe. As the population in Europe ages, the burden of the disease on society will increase. In a united front with other European nations, Spain adopted the Helsingborg Declaration on European Stroke Strategies in 2006, which is a statement of the overall aims and goals of stroke management agreed upon by the WHO to be achieved by 2015. Of the several goals, goal two, management of acute stroke, is especially relevant to the telestroke programme and targets (4:201)

7.2 Commonwealth fund collaboration

Commonwealth fund was mentioned in the studies in the following contexts:

1) As reference: Australia (2014a), "Statistical Data Integration Involving Commonwealth Data",www.nss.gov.au/nss/home.nsf/NSS/0E887A88A9224F8BCA2577F20016FE5D?opendocument, accessed 30 July 2014.
2) As co-financer of developing the ICT benchmarking tool: This multi-stakeholder project was first launched in 2008. It was co-financed with grants by Health Canada, the Commonwealth Fund (CMW), the European Commission (Directorate General for Health and Consumers and Directorate General Connect), the Ministry of Health of Spain, the German Federal Health Ministry, and the Office of the National Coordinator for Health Information Technology (ONC) at the US Department of Health and Human Services. Three international workshops were held to advance this work, the first in Barcelona in 2010 co-sponsored by the EC and the Ministry of Health of Spain, the second in Paris in 2011 co-sponsored by the ONC and the CMW Fund, and the third in Brussels co-sponsored by the EC DG Connect.(5:59)
3) As conductor of ICT surveys: How have other Health ICT surveys encouraged responses?• The Commonwealth Fund: Incentives: • Specific amounts were: $25 per response in the US and Canada; $50 in Australia; 30 pounds in the UK (5:58)

7.3 EU collaboration

European union was mentioned in the studies in the following roles:

1) As a funder of efforts to advance health system performance and quality through analysis of large-scale databases : A few key examples from the EU seventh framework research programme are EU-ADR, EuroHOPE, and ECHO.(1:256) This project was co-financed by a grant provided by the Directorate General for Health and Consumers of the European Commission. (4:1)
2) As a participant in projects: For development of eHealth benchmarking tools, a multi-stakeholder project was first launched in 2008. It was co-financed with grants by Health Canada, the **Commonwealth Fund** (CMW), the **European Commission** (Directorate General for Health and Consumers and Directorate General Connect), the Ministry of Health of Spain, the German Federal Health Ministry, and the Office of the National Coordinator for Health Information Technology (ONC) at the US Department of Health and Human Services. Three international workshops were held to advance this work, the first in Barcelona in 2010 co-sponsored by the EC and the Ministry of Health of Spain, the second in Paris in 2011 co-sponsored by the ONC and the CMW Fund, and the third in Brussels co-sponsored by the EC DG Connect. An OECD Expert Group was collated representing 30 countries (including India, Brazil, and Egypt, as well as the **European**

Commission (EC), the World Health Organisation (WHO) and BIAC (Business and Industry Advisory Committee) and four expert sub-groups or Task Forces, chaired respectively by J. Zelmer (Canada), P. Hämäläinen (Finland), M. Sprenger (the Netherlands), J. Thorpe (United Kingdom) to bring a range of relevant expertise and country representation to this initiative. Within the OECD Secretariat, this project was developed by Elettra Ronchi who acted as project manager and coordinator. The project was carried out in close cooperation with Dr Ashish Jha (Harvard University School of Public Health), who led this effort as Chair of the virtual OECD Expert Group on benchmarking health information and technologies, and Julia Adler-Milstein (University of Michigan). (5:2)

3) As a reference to results of projects supporting policy priorities (1:207)
4) As implementer of OECD guidelines: These [OECD privacy] principles were subsequently reflected in the 1995 Data Protection Directive of the European Union (95-46-EC) that regulates the processing of personal information. In the European Union, a directive is a legal act that is required as a result of an EU treaty. Directives are binding for member states and each state is required to incorporate the directive into law within the time period specified in the directive.
5) As participant in the OECD work: The OECD member countries are: Australia, Austria, Belgium, Canada, Chile, the Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Japan, Korea,Luxembourg, Mexico, the Netherlands, New Zealand, Norway, Poland, Portugal, the Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey, the United Kingdom and the United States. The European Union takes part in the work of the OECD.(1:265)

7.4 HIMSS collaboration

1) As a source for data on country-specific plans or policies to develop national EHR systems: Singapore http://69.59.162.218/HIMSS2012/(3:365)
2) As reference: Pan, E. (2004), "The Value of Healthcare Information Exchange and Interoperability", Center for Information Technology Leadership (HIMSS), Washington, D.C. (4:42)

7.5 Areas of collaboration

Chapter (4.3) on working methods describes collaborative activities in the OECD work, which are one way of exchanging knowledge. Study 4 reveals several areas where international collaboration is needed, in particular to:

- support countries in developing the norms necessary for governments to certify or accredit data processors;
- develop guidance for the implementation of project approval bodies;
- ensure that there are sufficient agreed international standards for data coding and interoperability;
- support countries to evaluate which national legal frameworks for the protection of health information privacy provide adequate protections to facilitate multi-country statistical and research projects;
- review current practices in patient consent and in waivers to consent to reach a common understanding about mechanisms that are privacy protective;
- review developments in data security risks and threats and mechanisms to address them; and

- explore mechanisms to engage the public in discussion about data and its governance to ensure that there is good public awareness of health data, the benefits of its use, its protection, and the rights of data subjects. (1:279)

In addition, there are or have been collaborative activities ongoing in different areas, with participation of EU- and non-EU-countries for mutual knowledge exchange and learning, as well as activities, where there are developments made both in the EU and OECD

7.6 Collaboration in Benchmarking for health ICTs

For development of eHealth benchmarking tools, a multi-stakeholder project was first launched in 2008. It was co-financed with grants by Health Canada, the **Commonwealth Fund** (CMW), the **European Commission** (Directorate General for Health and Consumers and Directorate General Connect), the Ministry of Health of Spain, the German Federal Health Ministry, and the Office of the National Coordinator for Health Information Technology (ONC) at the US Department of Health and Human Services. Three international workshops were held to advance this work, the first in Barcelona in 2010 co-sponsored by the EC and the Ministry of Health of Spain, the second in Paris in 2011 co-sponsored by the ONC and the CMW Fund, and the third in Brussels co-sponsored by the EC DG Connect. An OECD Expert Group was collated representing 30 countries (including India, Brazil, and Egypt, as well as the **European Commission (EC), the World Health Organisation (WHO) and BIAC (Business and Industry Advisory Committee)** and four expert sub-groups or Task Forces, chaired respectively by J. Zelmer (Canada), P. Hämäläinen (Finland), M. Sprenger (the Netherlands), J. Thorpe (United Kingdom) to bring a range of relevant expertise and country representation to this initiative. Within the OECD Secretariat, this project was developed by Elettra Ronchi who acted as project manager and coordinator. The project was carried out in close cooperation with Dr Ashish Jha (Harvard University School of Public Health), who led this effort as Chair of the virtual OECD Expert Group on benchmarking health information and technologies, and Julia Adler-Milstein (University of Michigan). (5:2) The project developed and piloted a model survey for benchmarking health ICTs, to be used by the member states.

7.7 Collaboration in advancing health system performance by use of health data

For ten years, the OECD Health Care Quality Indicators Programme has been developing and reporting indicators of quality and performance across the domains of primary care, patient safety, hospitalisation outcomes and cancer care. This collaborative initiative has resulted in progress in the methodologies for comparable indicators, as well as progress in the development of the underlying data that enable the indicators. As of 2013, however, only one-half of OECD countries were able to report quality indicators requiring dataset linkages, such as mortality within 30 days after hospital admission for AMI or for Ischemic stroke (OECD, 2013b). Only seven countries were able to report on excess mortality from schizophrenia or from bipolar disorder.

7.8 Collaboration in Health data protection

The OECD privacy guidelines from 1980 were subsequently reflected in the 1995 Data Protection Directive of the European Union (95-46-EC) that regulates the processing of personal information. In the European Union, a directive is a legal act that is required as a result of an EU treaty. Directives are binding for member states and each state is required to incorporate the directive into law within the time period specified in the directive. (1:260)

In Europe, the European Directive 95/46 applies to countries of the European Economic Area (EEA), which includes all EU countries and Iceland, Liechtenstein and Norway. The directive

enables the free movement of personal data in Europe and states that personal data can only be transferred to countries outside the European Union and the EEA when an adequate level of protection is guaranteed. With the EEA, all countries would have the same protection of privacy as was required by the directive. As a result, the European countries participating in the OECD study on health data governance have a clear and similar interpretation of data sharing requirements with foreign entities. Data may be shared if they are fully anonymised, such as aggregated data. If data are identifiable or de-identified but still carry a re-identification risk, then the data privacy protection legislation in the applicant's country must be evaluated as providing adequate protection. 1:262

Similar to Europe, Israel will consider foreign applicants from countries within the European Union or whose data protection legislations are similar to those of the European Union. New Zealand will also consider foreign applications for access to data where the country's privacy legislation offers equivalent protections to that of New Zealand. (1:264)