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Intelligent system governance, stewardship and resource allocation

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Health systems could harness information and communications (ICT) technology and data in several ways to improve governance and guide resource allocation. Despite the availability of technologies, institutional and organisational artefacts of the pre-digital era are a barrier to progress. While digitalisation makes long-standing fragmentation more apparent and can catalyse reforms, it can also lead to further fragmentation if ICT systems are not interoperable. Policy also needs to constrain the incentives for private owners of data to turn them into a scarce commodity and prevent other entities with legitimate interests from accessing and analysing them. Countries can make progress by defining comprehensive and inter-sectoral strategies, by instituting data governance frameworks and infrastructure to make data readily available for legitimate purposes while protecting privacy, and by investing heavily in capacity to generate knowledge from data and to deploy this knowledge to improve health system performance.

8.1. Introduction

Health systems are notoriously complex. Managing, governing and steering such systems in a way that achieves public policy objectives is a challenge for decision makers across the world.

Increasing digitalisation and new information and communication technologies (ICT) have the potential to fundamentally change health systems at all levels – from prevention, to care delivery, to policy development, implementation and evaluation. At the same time, the amount of potentially useful data generated within and outside of health systems is increasing rapidly. For policy makers, these developments pose new challenges. But they also provide opportunities to use ICT more effectively and turn the vast amounts of data into actionable information and knowledge, and increase the ability to govern, steer and direct health systems.

This chapter discusses how ICT, especially the secondary use of the increasing amount of data generated within and outside of health systems, can be harnessed to improve their governance and stewardship. It focuses on a number of distinct activities that are part of health system governance – in particular resource allocation and monitoring and improving the quality of services.

The Chapter comprises four main Sections. Following a brief section defining governance in a health system context, Sections 8.2 and 8.3 outline how ICT and electronic data can be used for governance and reviews progress made so far. Section 8.4 identifies the most important barriers to and enablers of greater use of data for governance and analyses risks of the increased availability of data. Section 8.5 outlines possible ways forward for governments, focusing on three key activities: developing a systemic digital strategy, instituting a strong health data governance framework,¹ and building requisite policy capacity.

Throughout, the Chapter provides examples from OECD countries of how data can be put to use in health system governance. Examples are drawn from the survey conducted in the research from this report, interviews with experts and the published literature.

8.1.1. Governance is a comprehensive process to achieve health system goals

In general terms, governance is *“the exercise of political, economic and administrative authority necessary to manage a nation’s affairs... the process by which public institutions conduct public affairs and manage public resources”* (OECD, 2006, p. 147^[11]). Governance is a means for governments to work towards policy objectives.

For health systems more specifically, WHO defines governance as *a wide range of steering and rule-making related functions carried out by governments and decisions makers as they seek to achieve national health policy objectives* (WHO, 2013^[2]). Health policy objectives can be more or less specific and expressed in health care laws or national strategic plans. The World Health Report 2000, which described the workings of health systems in four functions, identified stewardship as one of them. This function entails overseeing and guiding the working and development of the health actions of nations, a role requiring vision, intelligence and influence (WHO, 2000^[3]).

Governance, in the health context, therefore includes not only system management through use of ICT and data, but also guidance of the ICT industry, technological developments and data governance, so that the right technologies are developed, the right data are generated in the right format and that both can be transformed into actionable information in the health system. It includes regulation and design of incentives that steer all stakeholders in the system, beyond government institutions, to invest in the technologies and services that help health systems attain their policy objectives.

This chapter takes a more narrow view of governance, focusing on a number of distinct governance activities: the identification of need for health care; quality monitoring and improvement; identifying waste

and low-value care and monitoring efficiency; and how these activities can guide resource allocation including provider payment. It also briefly touches on the role of governance in guiding the ICT industry.

8.2. Smart use of data can help improve effectiveness, equity and efficiency of health systems

Health systems generally aim to improve population health through the provision of services, including prevention, medical interventions and curative care. Given that resources to devote to addressing population health and other needs are – and will continue to be – scarce, this aim must be achieved within defined budgetary parameters.

The concepts of effectiveness, equity and efficiency are useful to understand how health systems contribute to population health. Although distinct, these three concepts are intricately linked and often referred to in relation to care quality, although they can equally be applied to public health policy interventions, for example. They can guide the allocation of resources in health systems to provide the right services to the right people at the right time while avoiding service provision to people who don't need them – minimising waste and increasing value for money.

Health services are **effective** if they deliver interventions that are safe, i.e. minimise the risk of harm, and that achieve desirable health outcomes (Carinci et al., 2015^[4]). Desirable outcomes include, for example, reductions in mortality and the prolongation of life, alleviation of disability, improvements in the quality of life and a positive patient experience.

Health services are **efficient** if they are effective at the lowest possible cost. Efficiency can thus be improved, for example, by making existing services safer and more effective, by adopting new services that are effective in achieving desirable outcomes, by replacing less effective services with more effective ones, by reducing the unit costs of effective services and by replacing more expensive services with cheaper ones that are equally effective. For example, nurse practitioners are able to perform many functions of physicians at lower cost.

Efficiency is also an important consideration when prioritising among different programmes, geographical areas, population groups, diseases and other health challenges (allocative efficiency). For example, preventive interventions may deliver greater returns at the margin through cost savings and health gains than interventions used to manage disease; a diabetes management programme may generate greater health gains than the same investment in cardiac surgery or cancer care (again, at the margin); region x would derive greater benefit from additional parcel of resourcing than region y.

Such trade-offs may be uncomfortable. But in a resource-constrained environment they are an unavoidable part of policy making and must be made, be it implicitly or explicitly. It is preferable that these decisions are explicit based on sound knowledge and evidence, which – as argued in this Chapter and in this report – can be generated by harnessing available data.

Equity requires that effective health services are delivered to all who can benefit (ibid.). Equity is often construed in terms of access to health care, because some people may legitimately choose not to receive a service they can benefit from, so that health systems are equitable if they provide “equal access for equal need” (Oliver and Mossialos, 2004^[5]).² A more equitable provision of services may also increase efficiency at the system-level. Providing access to services based on need, or capacity to benefit, will contribute more to achieving desirable outcomes overall versus a scenario where some people receive services they do not benefit from, implying waste, or where some people do not receive services they could benefit from, representing a missed opportunity to improve outcomes. On the other hand, prioritising the lowering of geographic, financial or cultural barriers to access for certain population groups in need can necessitate increased expenditure per unit of health gain and/or a reduction in funding for other competing priorities.

There are many ways through which greater use of data and ICT can help achieve the goals of effectiveness, equity or efficiency. For example, more accurate diagnoses and treatment decisions through using decision support systems and enhanced sharing of information between providers can prevent errors and increase patient safety (Banger and Graber, 2015^[6]).

However, the greatest opportunity arguably lies in better aligning health service design and delivery with population health needs. ICT and data are becoming increasingly available from various sources inside and outside of health systems. Secondary use of these data provide unique opportunities to identify care needs of distinct population groups and individual patients, design interventions to meet these needs, and target interventions to those people who are likely to benefit to deliver interventions more effectively and efficiently. These activities are at the core of health system governance and can reallocate resources to where they can generate the most benefit.

8.2.1. Health is lagging behind other industries in analytical use of data

Digitalisation has so far had a much more profound and transformative impact in sectors of the economy not related to health. The financial services, retail, entertainment and hospitality sectors, for example, have harnessed digital technology for more than a decade to deliver better products and services, increase the value for customers, while maintaining and increasing profitability.

For example, analysis of customer data is used the airline industry, banking and retail to improve responsiveness to needs and expectations. In insurance, predictive analytics and Artificial Intelligence (AI) provide information on expected behaviour and activity. Large datasets are used to stratify populations for more effective and targeted interventions in areas ranging from retail to politics. Real-time data analytics are able to identify fraud by detecting even small deviations from expected activity (Bates et al., 2018^[7]). By simply making existing data publicly available, the Transport Authority of London has generated estimated savings of GBP 130 million per annum for customers, road users as well as public and commercial entities (OECD, 2019^[8]). Table 8.1 provides examples of existing use of data in other sectors, which can be applicable to health in different ways and could potentially increase the ability of health systems to be responsive to individual patient needs and support governments in performance assessment.

Firms in these sectors have recognised data as being the key resource for better product design and a source of knowledge about their customers. They have also recognised the non-rivalrous nature of data, and put these to work to create value. For example, routine commercial flights generate a large volume of data on the performance of the aircraft, its component parts, as well as real-time weather information. These data are fed back and analysed by airlines, regulators and manufacturers along the entire supply chain to continually improve performance. Air travel is now one of the safest modes of transport available, and has never been cheaper or more accessible to consumers. A similar data-driven approach in agriculture techniques has the potential to improve global crop yields by up to 30% (OECD, 2017^[9]).

As for-profit enterprises, firms in non-health industries have strong incentives for putting customers at the centre and for personalising their offers. As firms increasingly provide digital products and services and rely on digital technology for marketing and customer communication, they have invested heavily in establishing digital tools and data repositories. They have also invested in analytical capability to gain insights and take action.

Table 8.1. Uses of data in non-health sectors

Big data uses	Sector	Use-case	Purpose	Possible use in health systems
Customer sentiment analysis	Airlines, banking, retail	Analyses of social media posts on products and experiences	Increased responsiveness to customers needs and desires	Health systems could use similar strategies to improve patient experience and build trust in health systems and health care settings
Predictive support	Insurance, education	Analyses of credit reports and customer risk “appetite”, support student academic performance by providing guidance about needed improvements	Future behaviour is anticipated, and prevented (low grades) or encouraged	Investigating relationships between demographics, risk factors and health outcomes
Behavioural analytics	Banks, restaurant chains	Analyses of browsing and purchasing trends	Prediction of “life changes” such as pregnancy based on customer purchases	Predicting future health service use based on past utilisation and behaviour
Customer segmentation	Retail, entertainment	Analyses of social media information and purchase history to gain insight into group preferences	Campaigns for specific demographics, reducing promotional spending on individuals who are not potential clients	Personalising care plans, targeting clinical and prescription guidelines to more specific patient groups, to reduce unnecessary use
Fraud detection	Insurance, credit cards	Alerts when spending deviates from normal patterns	Identification of fraudulent claims	Reducing incidence of DRG creep, billing for unperformed services, and identification of unnecessary provision and unwarranted variation

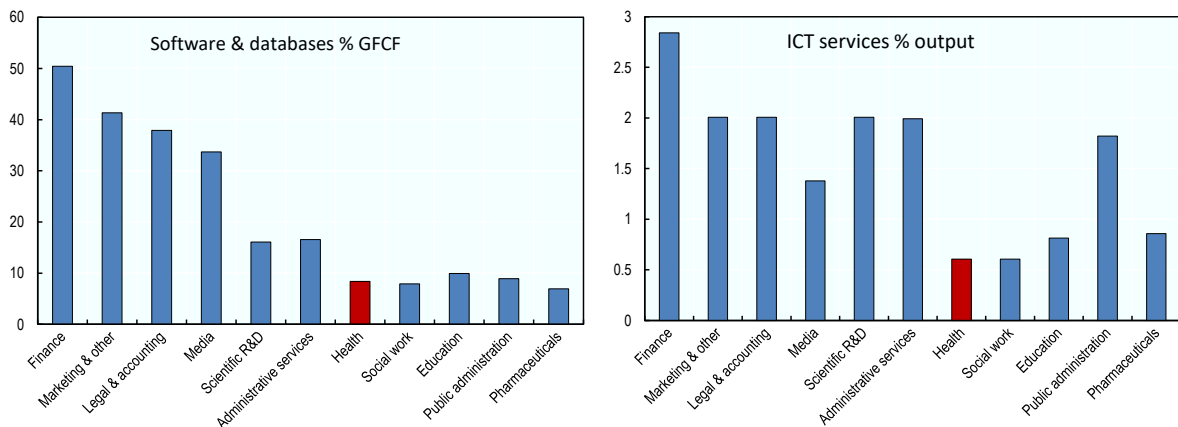
Source: Adapted from Bates et al. (2018^[7]), “Why policymakers should care about “big data” in healthcare”, <https://doi.org/10.1016/j.hlpt.2018.04.006>.

The health sector provides a stark contrast. Despite the mountains of data generated during routine health care activity, harnessing these data to, for example, assess the performance of medical products or therapies is rare; in some health systems, it is not possible to detect when a patient is re-admitted to hospital if the re-admission occurs at a different place. Investment in ICT infrastructure is much lower in the health sector than in other industries. While the banking industry, for example, invests 12% of its revenue in information systems, health systems in OECD countries only invest 2-4% of their expenditures (OECD/WHO/World Bank Group, 2018^[10]). Although expenditure on tangible products – such as ICT hardware – is at a similar level to other information-intensive service industries including education, finance and public administration, investment in *intangible* products such as software and databases and the purchases of ICT services as a percentage of output are comparatively modest (Figure 8.1).

It should be stressed that other sectors were not transformed simply by the adoption of digital technologies into existing business models. Rather, industries have realised opportunities offered by ICT by fundamentally changing their organisational structures, processes, expertise and underlying attitudes. The speed with which this has happened in some sectors to deliver better services is in stark contrast with health. This has been evident in some industries where disruptive innovators have created improved ways of performing tasks, which has stimulated adaptation among bigger players. Not too long ago, electronic banking was deemed revolutionary. Now the word *electronic* is redundant. Small-scale disruption is adopted, evaluated and scaled to improve industry performance as a whole. Internet-based companies founded just a few years ago have grown rapidly.

Figure 8.1. Investment in software, databases and ICT services by the health and other industries

Investment in software and databases as a % of non-residential GFCF; purchases of intermediate ICT services as a % of output



Note: Gross fixed capital formation (GFCF) is a measure of spending on fixed assets. Countries covered: Australia, Austria, Denmark, Finland, France, Italy, Japan, the Netherlands, Norway, Sweden, the United Kingdom, and the United States.

Source: Calvino et al. (2018^[11]), "A taxonomy of digital intensive sectors", <https://dx.doi.org/10.1787/f404736a-en>.

However, the ubiquity of data also allows for their misuse and abuse. Stakeholders need to build trust that data are used for legitimate purposes but that such use also respects privacy and personal preferences. Governments need to put in place laws and data governance frameworks that encourage legitimate use while preventing and penalising abuse. The European General Data Protection Regulation (GDPR),³ for example, which is in force in the European Union since 2018, provides strong protection of personal data. At the same time, it recognises data concerning health as a special category of personal data and provides for a number of exceptions to general data protection principles under which health data can be used subject to defined safeguards for legitimate purposes, such as public health policy, research and health system governance.

8.3. Data and ICT can enhance governance but progress in countries is slow

Using ICT and data can improve health system governance and stewardship in four key ways: 1) needs assessment and needs-based resource allocation; 2) the monitoring and improvement of health service quality; 3) identification of low-value care and monitoring of efficiency; and 4) defining new provider payment models that incentivise the improvement of health outcomes. However, in many OECD countries progress towards realising the potential of these opportunities remains slow thus far. Many examples of effective use of ICT and data to improve governance are limited to relatively small-scale projects and certain parts of health systems.

8.3.1. Needs assessment tools and needs-based resource allocation are under-used

Health data harbour great potential knowledge to help improve the allocation of resources based on health need. This concerns, for example, allocation between geographical areas, population groups, diseases and levels of care as well as distinct models of service delivery. Needs-based allocation of resources greatly improves equity but at the same time, by redeploying resources to where they can improve health outcomes most, can also drive health system effectiveness and efficiency.

Needs-based resourcing can improve equity and efficiency but is the exception, not the norm

Needs assessment is a linchpin of governance and resource allocation. Linking up data from health and social care with behavioural and socio-economic data to predict health needs and basing resource allocation on such measures of need can improve effectiveness, efficiency and equity at the same time. Predictive models can be applied to large datasets to predict future health events and allow for stratification of an entire population according to relevant risk metrics.

Such models may use, for example, statistical analyses or machine learning algorithms to establish relationships between a set of observed individual characteristics of persons, such as age, gender, diagnoses and treatments, environmental conditions or place of residence, and the risk measure of interest, such as patient complexity, risk of readmission to hospital, length of hospital stays, likelihood of adverse events, future health care expenditure or death (Nalin et al., 2016^[12]). More resources can then be allocated to people whose health outcomes can be improved. On an individual level, people can be prioritised for appropriate health care interventions, such as screening, preventive measures or, for the most complex patients, enrolment into personalised integrated care.

Where primary care is paid through capitation, there is a long tradition of using routine data to adjust the allocation of resources for differences in need. In the most basic form, capitation is based on age- and socioeconomic factors as proxies for need. However, most health systems in OECD countries apply more advanced algorithms with diagnostic data from health records to adjust capitation, combining health records with enrolment and residency data. Such principles can be applied to various levels of resource allocation.

Finland is currently reorganising its health system into 18 new regional health administrations, to be funded primarily by national budget resources. With large differences in need across the country, the government seeks to develop a risk-adjusted formula for both provider payment purposes and for allocating national funds across the 18 regional administrations (Cylus et al., 2018^[13]). The implementation of a new monitoring framework and data management system is also part of the country's health and social care system reform (also see Section 8.4.3). The integration of data from all providers of health and social services, as well as socio-economic data, is intended to inform the needs-based allocation of budgets once the new health regions are formed.

Despite the benefits of the secondary use of routine data for needs-based resource allocation, this has not yet been widely adopted across OECD countries. Secondary use of routine health care data is relatively common for risk-adjustment of capitation payments while other uses, such as for budget allocation or targeting of services, are uncommon (Jakab et al., 2018^[14]). However, a number of tools are already available and some examples in OECD countries illustrate how such processes can be implemented. These examples include performance-based budgeting, risk stratification processes, and the creation of virtual registries to inform resource allocation.

Performance-based budgeting relies on good data

Many OECD countries have national systems in place to monitor the performance of health care providers (Beazley et al., 2019^[15]). Performance data, such as risk-adjusted measures of mortality or other health outcomes at the regional or hospital level, indicators related to the process of care, or patient-reported experience measures (PREMs) are sometimes used to inform budgeting and resource allocation across programs or regions. This is referred to as performance-based budgeting.

However, in most countries the link between performance and budgeting is relatively loose, with performance information presented as background in budgeting discussions or indirect links between performance and spending decisions. Only a limited number of countries establish a direct link between

performance measurement systems and resource allocation. Also, performance-based budget allocations do generally not represent a significant share of the overall budget (ibid.).

In an OECD survey conducted between November 2017 and May 2018, only Chile, Italy, Finland, Lithuania, and Luxembourg reported that data from a national performance monitoring system were used to adjust budget allocations to devolved health care payers or individual provider organisations, such as primary care practices and hospitals (ibid.). Norway has adopted a performance-based budgeting system to determine budget allocations to its four regional health authorities based on indicators related to health outcomes, health care processes and patient experience (ibid.). A system of health terminology for primary documentation, linked to classifications and reimbursement codes for statistics and funding, is being built to make the reporting more efficient, and providing a richer information base for analysis and policy making.

Risk stratification can improve how resources are deployed

Spain serves as a good example of risk stratification to enhance resource allocation across an entire population. The Catalan Health Institute (ICS) developed and implemented a population risk stratification system referred to as Morbidity-Adjusted Groups (*Grupos de Morbilidad Ajustados – GMA*). The Spanish Ministry of Health, Consumer Affairs and Social Wellbeing (MSCBS) subsequently promoted the expansion of GMA across Spain, and, by the end of 2015, the tool was implemented in 14 of the 17 Spanish Autonomous Regions. Nine regions are currently using it systematically. Further information on the GMA system is in Box 8.1.

GMAs serve a variety of purposes. Case finding for specific models of care is one of the most common uses (Cerezo Cerezo and Arias López, 2018^[16]). In some regions, GMA results are displayed in electronic health records (EHRs) to support decision-making or in developing of case management programs based in primary care.

At the system-level, GMAs are deployed in predictive modelling and forecasting of health care demand, in macro-level resource allocation (e.g. through setting needs-based budgets, determining capitation payments for medicines and needs-based health workforce planning), and in public health monitoring and identifying people to include in epidemiological and clinical studies (ibid.).

In addition to identifying complex patients, GMAs are used in Madrid for risk-adjustment of a capitated budget for publicly funded prescription medicines assigned to physicians working in primary care centres (Comunidad de Madrid, 2018^[17]). In Catalonia, the GMA system is also used for case finding and for setting risk-adjusted capitated budgets of primary care teams (Cerezo Cerezo and Arias López, 2018^[16]; Nalin et al., 2016^[12]; Vela et al., 2018^[18]).

The wide adoption of the GMA system across Spanish regions has been considered an indication of its success. Regions reported that they are particularly satisfied with the ease of use, the versatility of the system for multiple purposes, and in some cases the indirect effect the implementation has had on coding practices by health professionals and data quality (MSCBS, 2018^[19]). While no estimates of total cost across all regions, including ongoing operation of the system, are available, the direct cost of implementation to the Spanish Ministry was under EUR 0.5 million. Because the system was developed locally rather than purchased from a commercial vendor, regions are not required to pay ongoing license fees.⁴

Box 8.1. Morbidity-Adjusted Groups (*Grupos de Morbilidad Ajustados – GMA*) for population stratification in Spain

The Morbidity-Adjusted Groups (GMA) system is implemented with the goal of transitioning from a disease-centred to a patient-centred model of health care delivery, by identifying individual health needs and implementing needs-based models of care and resource allocation. It was initially launched in Catalonia in 2012, and subsequently extended to 13 additional autonomous regions of Spain.

GMA was initially developed by the Catalan Health Institute (ICS). After experimenting with off-the-shelf software solutions for population stratification since 2009, ICS developed this tool internally for use with local routine data and to meet needs for patient management in primary care. Later, as part of its Chronic Disease Strategy introduced in 2012, the Spanish Ministry of Health, Consumer Affairs and Social Wellbeing (MSCBS) promoted the expansion of GMA to the vast majority of regions.

The system stratifies the entire population into 31 distinct GMA groups. Diagnosis codes are used to assign each person to a morbidity group: healthy population, pregnancy and/or labour, acute disease, chronic disease in 1 system, chronic disease in 2 or 3 systems, chronic disease in ≥ 4 systems, and cancer. Acute diagnoses are considered only if they are recent (usually within the previous year) while chronic diagnoses are considered regardless of the date. A complexity index is calculated for each person based on analysis of past resource use variables, such as primary care visits and pharmaceutical prescriptions, mortality data and risk of hospital admission. Each morbidity group except the healthy population is stratified into 5 complexity subgroups. In addition, a label is assigned to each person with information on the most relevant diseases, from a list of 80 prioritised health problems.

Data sources are region-specific, but generally comprise EHR data from primary care providers and hospitals. Every insured person has a unique ID, which allows for data linkage and inclusion of the entire population of each autonomous region. By 2015, 38 million people were captured by the system across 14 of 17 regions, including Catalonia. Because EHR data of citizens covered by public health insurance are used as a main data source, people who are uninsured are not captured. About 1% of the Spanish population was uninsured in 2017, ranging from 0.3% to 3.8% depending on the region.

The GMA system was expected, in particular, to help improve care for people with chronic disease and multi-morbidity, who now represent a large proportion of the Spanish population. GMAs have been found to accurately predict parameters that are relevant for needs-based planning and resource allocation, such as primary care visits, unplanned hospitalisations and pharmaceutical spending per patient. No evaluations of their effect on health outcomes or health care costs are available to date. The Spanish MSCBS funded the implementation of GMA in regions other than Catalonia with EUR 472 000.

A main limitation is that GMAs are based on routine health care data and do not capture patient characteristics that are not captured and coded in such data, for example functional and cognitive capacity or social circumstances that may affect patient complexity. In addition, general inaccuracy in coding and difficulty to capture mental health problems were recognised as limitations.

Source: Based on Cerezo Cerezo and Arias López (2018^[16]) "Population Stratification: A fundamental instrument used for population health management in Spain", http://www.euro.who.int/_data/assets/pdf_file/0006/364191/gpb-population-stratification-spain.pdf?ua=1; Monterde, Vela and Clèries (2016^[20]), "Los grupos de morbilidad ajustados: nuevo agrupador de morbilidad poblacional de utilidad en el ámbito de la atención primaria", <http://dx.doi.org/10.1016/J.APRIM.2016.06.003>; MSCBS (2018^[19]) "Informe del proyecto de Estratificación de la Población por Grupos de Morbilidad Ajustados (GMA) en el Sistema Nacional de Salud (2014-2016)", https://www.mscbs.gob.es/organizacion/sns/planCalidadSNS/pdf/informeEstratificacionGMASNS_2014-2016.pdf; MSCBS (2018^[21]), "Población de 0 y más años, en porcentaje, cubierta por el sistema sanitario público, según la Encuesta Nacional de Salud de España 2017", <http://www.mscbs.gob.es/estadEstudios/sanidadDatos/tablas/tabla6.htm>.

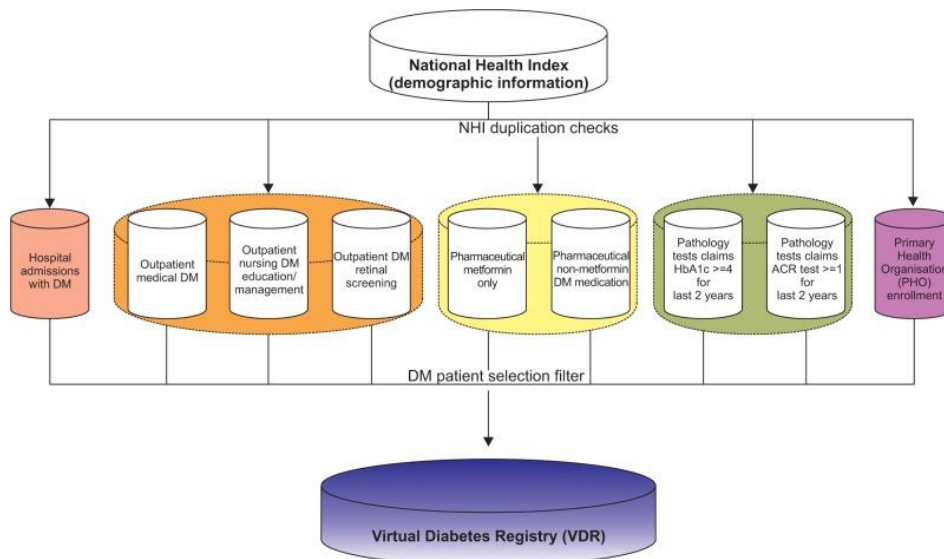
Virtual registries: a very efficient way to generate valuable knowledge

An estimated 30 million people in the United States (9% of the population) have diabetes but 7 million (24% of all cases) remain undiagnosed (CDC, 2017^[22]) because population-wide screening with laboratory tests would be too expensive. Models using data from electronic medical record have been demonstrated to deliver high predictive accuracy in identifying people with undiagnosed type 2 diabetes who should be prioritised for laboratory test-based screening (Anderson et al., 2016^[23]). It would be too expensive to include all people with diabetes in resource-intensive disease management programs. The cost-effectiveness of such programs therefore depends crucially on targeting those people who can benefit the most (Simcoe, Catillon and Gertler, 2019^[24]).

Health authorities in New Zealand are developing virtual registries for chronic diseases, also including diabetes, by extracting relevant data from a range of existing sources including EHRs, hospital admissions, primary care and pharmaceutical dispensing. Conventional, prospective disease registries can be costly to establish and maintain. Linking existing datasets to build them is an economical way to create an information repository that can inform a range of policy and practice decisions. For example, the virtual diabetes registry allows for disaggregating prevalence estimates to the level of District Health Boards, the local holders of health care budgets in New Zealand, and primary care practices (Figure 8.2). More resources can be directed at the areas with higher prevalence to make improvements to care (SAS, n.d.^[25]). The information can be used to monitor quality of care and its outcomes across regions. Also, data from the registry allows for predicting who may be at risk of developing diabetes so that health care providers can act accordingly (ibid.).

In New Zealand, routine data are also used to model entry into, geographical movements within, and exit from the health workforce to project the future availability of professionals. Projections are then compared to future demand for specific services, also modelled using routine health care data, to inform government policy on workforce supply (e.g. regulating immigration and professional training) and to incentivise professionals to practice in underserved areas.

Figure 8.2. Databases for Virtual Diabetes Registry in New Zealand



Note: DM : diabetes mellitus, ACR : albumin creatinine ratio.

Source: Jo and Drury (2015^[26]). "Development of a Virtual Diabetes Register using Information Technology in New Zealand"
<http://dx.doi.org/10.4258/hir.2015.21.1.49>.

8.3.2. Harnessing data for more effective quality monitoring and improvement

Data from various routine sources, such as EHRs, prescriptions and insurance claims, enable more granular monitoring of the quality of service delivery. ICT can transform routine electronic data into a powerful resource for monitoring and improvement at various levels of the health system. The use of routine data to manage biomedical technologies is addressed in Chapter 7. This section addresses monitoring performance and policy responses in health systems more generally.

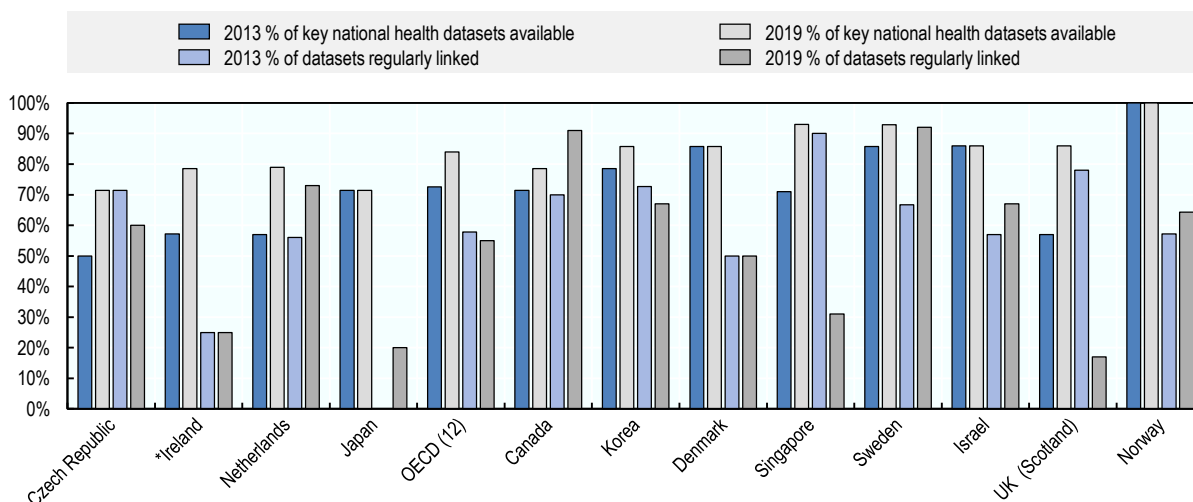
Routine data and their linkage enable more informed and responsive policy

Routine data have been used for some time to produce atlases of variation in care. Examples include the Australian Atlas of Healthcare Variation,⁵ the NHS Atlas of Variation in Healthcare in England⁶ and the Dartmouth Atlas of Health Care in the United States.⁷ While such high-level information does not usually explain the reasons for variations or break them down into warranted and unwarranted variation, it often serves as a starting point for more detailed quality reviews. Such reviews can then lead to redeployment of resources to areas with higher need or lower quality of care to increase effectiveness, efficiency and equity.

Harnessing more granular data from EHRs, for example, can begin to shed light on the reasons for the variation, and answer the key question of whether the variation is warranted by patient needs, characteristics and preferences, or not. For example, inter- and intra-country variation in procedures ranging from hysterectomy to percutaneous coronary intervention or total knee replacement, has long been established (OECD, 2014_[27]). Isolated studies that combine activity and outcomes data suggest that a significant proportion of some procedures may be performed unnecessarily (Ferket et al., 2017_[28]). Linking data on disease burden and service provision has suggested a serious mismatch between health need and cardiovascular care in Australian populations (Chew et al., 2016_[29]).

But linkage of such data – which are readily available – is rarely performed routinely and consistently, in spite of potentially equipping policy makers and system managers with knowledge to (a) gauge the appropriate rate for a given intervention, (b) identify where the appropriate number of interventions is (or is not) delivered, and (c) take corrective policy action. Figure 8.3 shows the number of countries where distinct health-related datasets are available and the percentage of these that are routinely linked across 11 OECD countries and Singapore. While availability appears to be growing, linkage is stagnant.

Figure 8.3. Availability of data is growing but their linkage appears stagnant



Note: These are preliminary data still missing several countries; only countries that responded to both the 2013 and 2019 survey are shown; *Ireland 2013 data used for 2019 (relevant survey section not completed in 2019).

Source: OECD (2019_[30]) "Survey on health data governance: preliminary results"; OECD (2015_[31]) "Health Data Governance: Privacy, Monitoring and Research", <https://dx.doi.org/10.1787/9789264244566-en>.

Assessing quality of care and health outcomes routinely

Routine data can be used to generate indicators that compare provider organisations against each other, map care pathways, to assess whether care is delivered according to guidelines and to gain insight into the outcomes achieved.

In Australia, for example, routine data from the National Hospital Data Collection (which collates administrative/morbidity data from hospitals in all Australian States and Territories) are used to generate comparative performance information. Indicators are published on a government website⁸ and include, for example, waiting times in emergency departments, rates of hospital-acquired infections and lengths of stays related to admissions for a range of conditions and interventions. This information can inform decision making at the State/Territory and Federal level.

In another example, researchers in Scotland linked patient-level data from health care encounters of patients with acute coronary syndrome, using the unique identifier common to all health care providers. The study relied only on routine data extracted from EHRs, meaning that no additional data collection was necessary. It analysed diagnoses, distinct care pathways and associated health outcomes, including mortality (Findlay et al., 2018^[32]). Results suggested, for example, that in the acute invasive pathway only 50% of patients received care in accordance with guidelines issued by the European Society of Cardiology and that the standard of care varied significantly between local admitting hospitals (ibid.).

EHR data have also been used in England to map care pathways of patients undergoing chemotherapy, finding that only about 5% of patients in the sample completed the planned six cycles of chemotherapy without having unplanned hospital contact (Baker et al., 2017^[33]). Such analyses can improve the understanding of *de facto* standards of care and can help identify sub-standard care and unmet needs, laying the basis for process improvement, or inform the improvement of clinical guidelines. Yet, they are mainly conducted on an ad-hoc basis despite the fact that they could be run routinely in a range of priority health system domains and challenges.

In Estonia, however, the Estonian Health Insurance Fund uses billing and e-prescription data to monitor care quality indicators on an ongoing basis. Clinical quality indicators are defined by professional societies, which also review preliminary results generated by the Estonian Health Insurance Fund. Clinical indicators include, for example, post-operative emergency rehospitalisation and mortality rates. In addition, there are a number of process-related indicators, such as waiting times and the share of day surgery in interventions that do not require hospitalisation. The quality of primary care and care integration are also monitored, through indicators such as hospital admissions and outpatient specialist consultations among patients with uncomplicated chronic diseases. Final results are presented to providers and published annually on the webpage of the Estonian Health Insurance Fund.⁹

While routine data have been used successfully for some time to monitor the quality of care, new ICT allows for more efficient and quicker secondary analysis of data for decision making, to support local quality improvement cycles and feed system-level quality monitoring. In a unique project in Germany, for instance, business intelligence tools are applied to monitor and improve the quality of integrated care through continuous improvement cycles (see Box 8.2). This example is instructive as it illustrates not only *generating* knowledge from existing data, but also *applying* this knowledge to drive improvement and positive transformation.

Box 8.2. Business Intelligence to support integrated health care: *Gesundes Kinzigital* in Germany

Private businesses use ICT extensively to monitor and improve business processes and the quality of their products. The ICT-supported process of transforming data into information and knowledge for the purpose of improvement has been commonly referred to as *business intelligence* (BI).

While many traditional models of health care delivery are still a long way from applying BI, the German health care analytics and consultancy firm OptiMedis has implemented BI solutions in monitoring and improving the quality of integrated care.

Since 2006 OptiMedis is a founding shareholder of *Gesundes Kinzigital*, an integrated care system that assumed full responsibility from social health insurance for health outcomes and health care delivery and all related costs in a local population of 31 000 people.

OptiMedis implemented an ICT infrastructure that centralised routine data from all care providers on diagnoses, operations, laboratory test results, medicines and medical aid prescriptions and insurance claims. After periodic extraction from sources such as electronic health records (EHRs) and claims databases, pseudonymous data are linked and cleaned in a core data warehouse and loaded to various analytical databases. Data are then transformed into information in analytical reports to support a Plan-Do-Study-Act (PDSA)-management cycle that comprises goal setting, performance measurement and improvement. Reports provide information, for example, on population structure and burden of disease to identify need, evaluation of the effectiveness of interventions for specific diseases against control groups selected from routine data, and periodic reports that benchmark performance of each individual provider against all other providers in a Donabedian structure-process-outcome quality framework.

Evaluations of *Gesundes Kinzigital* suggest that the model improved health care quality, in particular through the reduction of over-, under- and misuse of health services, and that people enrolled in the model had better health outcomes than those in control groups.

Source: Based on Pimperl, Schulte and Hildebrandt (2016^[34]). “Business Intelligence in the Context of Integrated Care Systems (ICS): Experiences from the ICS “*Gesundes Kinzigital*” in Germany”, http://dx.doi.org/10.1007/978-3-319-25226-1_2; Lupiañez-Villanueva and Theben (2014^[35]) “*Gesundes Kinzigital* (Germany), Case Study Report”, <http://dx.doi.org/10.2791/868740>.

It is possible to intervene at the community- and patient-levels

Data and ICT can also help analyse the quality of care and drive improvements at the level of individual patients and professionals. This can help ensure that increasingly decentralised and community-based services do not compromise the quality of care. Clinical decision-making aids, for example, can be integrated with tools that generate alerts or reminders when deviations from recommended care are detected (Shaw, Hines and Kielly-Carroll, 2018^[36]). Decision-making aids are discussed in Chapter 2 on care models and in Chapter 4 on the health workforce.

In the United States, machine learning techniques have been used to analyse large volumes of data from social media to identify the barriers to treatment for breast cancer and compare the importance of distinct barriers between ethnic groups (Freedman et al., 2016^[37]). The analysis showed, for example, that in nearly one-quarter of cases misperceptions, health care preferences, and spiritual, cultural or religious beliefs were a barrier, which was more common than physical barriers such as treatment tolerability and side effects (*ibid.*). Organisational factors in the health system were significant barriers for minorities (*ibid.*).

Preliminary results of the OECD Health Data Governance Survey 2019 indicate that several OECD countries now use key national health-related datasets to regularly report on health care quality or health system performance. The ubiquity of data and necessary digital infrastructure means that these types of

analyses can be performed more routinely. Again, however, linkage of several of the datasets for this purpose is uncommon. The barriers relate to capacity, including human capital and expertise, as well as data governance frameworks that do not enable the secure use of various types of personal data that can hold useful clues to health and health care.

8.3.3. Data can help identify low value care, but new services also require active monitoring and targeting to drive efficiency

It is a core role of governance to ensure that new services, including ICT-based and ICT-supported care delivery, drive health system efficiency. System-level efficiency gains, and in particular cost savings, do not come automatically with lower unit costs of service delivery, even when a new and cheaper service is equally or more effective. Greater reliance on ICT and more effective use of data provide great opportunities to monitor the effectiveness and efficiency of new services and the health system as a whole.

A wide range of datasets that can be used for such purposes already exist and opportunities will increase even further with technological advances. The magnitude of wasteful spending on health services is well-documented in OECD countries, with up to a fifth of resources deployed in a way that does not advance health and other policy objectives (OECD, 2017^[38]). Only an increasing capacity to collect and analyse electronic data in health systems allowed for the identification and quantification of unnecessary and even harmful services. Until recently, monitoring of unwarranted within-country variation in health service use, which is now common in many OECD countries, was not possible or prohibitively expensive. Also, data on variation in use are not routinely combined with outcomes to deliver information on high- and low-value care. Similar to other sectors of the economy, however, analytical capability will continue to increase and costs of data analysis will decrease.

New services often increase aggregate expenditure even if unit costs are lower

A common phenomenon associated with technological advances in health care is that new solutions drive down unit costs while total cost increases. New technologies that increase the effectiveness of care for a disease or reduce the unit cost of a service often also increase the volume of services provided, through uncovering unmet need or through expanding treatment-eligible populations because of changes in the risk/benefit profile of the service. While such changes can redeploy resources to where they are more effective, unit cost savings are thus often offset by additional volume. Examples of the introduction of new medical technology illustrate such patterns (OECD, 2017^[39]).

In the early 2000s, for example, percutaneous coronary intervention (PCI) became an alternative to coronary artery bypass grafting (CABG) in treatment of coronary artery disease. PCI is less invasive than open heart surgery and can be performed with local anaesthesia, reducing trauma and accelerating patient discharge. While a single PCI may be less costly than CABG, the number of PCIs performed has increased dramatically since the early 2000s (see, for example, McCreanor et al. (2018^[40]) or NICOR (2017^[41])). This increase can only be partly explained by a displacement of CABG. Growth in the number of procedures, and associated total cost, was also caused by more patients receiving PCI who would have previously been treated with medical therapy only, and PCI in increasingly sick patients, as techniques evolved and PCI-related complication rates fell (ibid.).

Similar patterns can occur in the introduction of new digital services. In a recent study of digital primary care services in California, only 12% of new digital consultations replaced face-to-face visits (Ashwood et al., 2017^[42]). Digital consultations had a lower cost than traditional visits. However, some of the additional visits (88% of total activity) likely met incremental demand while some possibly substituted services previously met by services with even lower costs, such as community nursing. While cheaper than face-to-face primary care visits, the new service did not generate aggregate cost savings for the health system. Whether it made the system more efficient depends on whether the new services led to more-needs based service provision that improved health outcomes at the lower unit cost.

Opportunities for assessing costs and effectiveness of care

A key prerequisite for allocating resources efficiently in health systems is information on the relative effectiveness and costs of interventions, typically generated through health technology assessment (HTA).

HTA is one area where the use of data-based evidence to make policy has a strong tradition. As health system governance has experienced increasing attention for at least two decades, some concrete governance tools were created. For example, introducing new medicines and health technologies based on a rigorous HTA process has become common since the 1990s and is today an integrated part of managing health system resources in many OECD countries (Panteli and Busse, 2019^[43]). Although this has not always gone beyond new technologies, some initiatives that aim to provide evidence for better resource allocation have developed into well-known tools and institutionalised platforms. These include the Cochrane Collaboration or the WHO Health Evidence Network.

As methods for comparative effectiveness studies using non-randomised data are being developed, the wealth of routine data accumulating in health systems represent a great opportunity to expand HTA. Increased use of HTA can inform strategic purchasing. Payers and providers have a shared interest in creating information systems and driving the development and use of data for HTA as a basis for strategic purchasing and a more efficient allocation of resources (Mathauer, Dale and Meessen, 2017^[44]). An environment with more accessible and broader sets of data provides opportunities to develop HTA and inform purchasing decisions in at least three different ways:

1. It will be possible to expand HTA into new areas of services and technology, which have previously not been scrutinised the same way in terms of costs and effectiveness. The secondary use of routine data can decrease the cost of HTA significantly. Lower costs can also allow for periodic re-evaluations rather than only evaluating new technology when it is introduced.
2. Wider datasets can also enable assessments of interventions for more narrow population sub-groups. In an analogy with precision or personalised medicine, this has given birth to the concept of “precision health economics” (Chen et al., 2016^[45]). This can help inform decision-making and as well as tailor services to smaller patient groups or individuals (see also Chapter 5).
3. Combining wider spectra of data sources from various population groups can support a more comprehensive analysis of both societal costs and value (Capone et al., 2015^[46]). For example, some innovations in health using new data and analytical techniques do not necessarily improve clinical outcomes but instead increase responsiveness and access (e.g. decrease the time need for response to a given diagnosis), which has a value to patients that is not often recognised in current models of value assessments (Albrecht et al., 2018^[47]). Traditional cost-effectiveness evaluations of new technologies relate direct and indirect costs to health outcomes (or their equivalent in terms of monetary value in a cost-benefit analysis). However, these typically include the value only from a clinical perspective.

Finally, in marketing authorisation, coverage and pricing of medicines, the use of routine electronic data is making progress, creating new ways of assessing products and increasing the ability to reassess products once they have been in use for some time (see also Chapter 7).

Data linkage can facilitate the generation of much more accurate information on the costs of illness. Researchers in New Zealand, for example, linked 7 years of (publicly funded) hospital, outpatient, pharmaceutical, laboratory testing and primary care data for the entire population at the individual person-level. The analysis considered 18.9 million person-years of data to assess the expenditure related to six chronic conditions (cancer, CVD, diabetes, musculoskeletal, neurological, and chronic lung/kidney/liver (LLK) disease) in isolation and in ‘co-morbidity pairs’. Results suggested *inter alia*: greatest expenditure in the year of diagnosis and the year of death; co-morbidity resulted in greater expenditure than the expected sum of the conditions in isolation (and that this was more pronounced at younger ages); at the population

level, 23.8% of total health care expenditure was attributable to this super-additive cost of co-morbidity (Blakely et al., 2019^[48]).

Such precise information on expenditure along the lifespan and across diseases can be extremely valuable to policy makers grappling with vexing questions on how best to prevent and manage chronic disease across populations. It relies on linkage of various sources of available data and the capacity to perform meaningful analysis on them.

8.3.4. Provider payment can incentivise improvement using data

The way health services are paid for is major barrier to making health systems more effective and efficient. The rise of chronic diseases and longer life spans requires that service delivery should be approached in a more longitudinal and coordinated way that crosses silos and boundaries between health sectors and settings.

New and data-rich environments in health care offer opportunities for developing more strategic provider payment systems that tie payments to delivering complete care packages that achieve the ultimate purpose of health services – improving health as efficiently as possible. Remunerating individual service parcels is not appropriate for longitudinal and coordinated care delivery that crosses boundaries between different providers to meet the challenges of chronic diseases and longer life spans. However, for realising the potential of data in provider payment, current payment mechanisms tied to the volume of services delivered also require reform to better support the use of data and the adoption of ICT.

Health services have historically been highly labour-intensive and while some capital investments, for example in training and infrastructure, were always necessary, a large portion of the total cost of services was variable and incurred marginally with provision of each additional parcel of services. Digital services and processes that rely heavily on ICT, on the other hand, may require large upfront investments in developing, evaluating and implementing technology, while services can often be delivered at relatively low marginal cost (OECD, 2019^[8]).¹⁰

Broadening the scope of payment for services

New digital technology and wider and more integrated datasets can facilitate the implementation of outcome-based payments, even if payment mechanisms remain difficult to design.

New payment systems in health care to encourage integration across entire care pathways, better outcomes and efficiency have been discussed for a long time. Three payment models to meet the challenges of rising patient complexity and achieve policy objectives include: 1) Additional payments made before, during or after service delivery for specified outputs or outcomes, for example, pay-for-performance based on agreed metrics or indicators; 2) Bundling – a combined, single payment for entire care cycles across settings and including primary care, imaging and diagnostic tests, and pathology, rehabilitation and follow-up care; 3) Population-based payment, in which groups of health providers receive payments on the basis of the population covered, in order to provide most health care services for that population (OECD, 2016^[49]).

New payment models vary in their design, incentives and structure. But they have one thing in common: success relies on strong information infrastructure with the capacity to integrate data on activities, processes, outputs and outcomes. The availability of longitudinal, patient-level data that can be integrated across a broad range of data sources, now provides new opportunities to expand these to include outcome-based payment.

With traditional data, compiled manually and kept in distinct information silos, many outcome measures that could be used as bases for payments were difficult to measure – this is part of the reason why fee-for-service (FFS) became a dominant payment mechanism. In addition, to avoid encouraging risk selection

and penalising providers for factors beyond their control, outcomes used as basis for provider payments have to be adjusted for underlying baseline risk. But baseline health status and data on dimensions such as time to recovery and return to normal activity, discomfort caused by adverse effects, sustainability of recovery and functional living, are crucial to design outcome-based payment schemes. These were difficult to capture in many health systems.

Linkage of clinical, administrative, financial and other data makes these new practices eminently possible. Payments can be bundled across a set of providers and activities, with data systems ensuring that each component is remunerated appropriately. In addition, the clinical and budgetary consequences of an error or adverse event at any point in the pathway become the responsibility of the entire team of providers, as opposed to the ones downstream to where the problem occurred. Good information systems can ensure that pay-for-performance is based on reliable data from several sources that can be more accurately adjusted for complexity and other confounders. Likewise, population-based remuneration can also be statistically adjusted to reflect health need, making it possible to transform care.

The possibilities for these innovative approaches to payment expand when health data are able to be linked with social care data. Enabling payment models that encompass a broader range of health determinants could yield better health and social dividends than the current fragmented approach. Integrating data in this way increases the accountability of each provider who contributes to a patient's care pathway.

Examples of such a holistic approach are few but some countries are laying the foundations. As part of its broader health system reform, Finland, for example, will use needs-adjusted capitation to allocated budgets to local counties and for paying health and social care services (Cylus et al., 2018^[13]).

In another example, the US Centers for Medicare and Medicaid Services (CMS) have made significant efforts since the adoption of the Affordable Care Act (ACA) to introduce schemes that link provider payment to the achievement of health outcomes rather than the volume of services provided (Burwell, 2015^[50]). The Hospital Value-Based Purchasing (VBP) Program for acute-care hospitals is one of the schemes that were implemented. It uses routine hospital data to generate indicators across the domains safety, clinical outcomes, efficiency and cost reduction and patient and caregiver experience.¹¹

So far, however, evidence of the effects of such payment schemes in the United States remains inconclusive and existing studies often find marginal, if any, effects on health outcomes (Damberg et al., 2014^[51]; Chee et al., 2016^[52]; Figueroa et al., 2016^[53]; Ryan et al., 2017^[54]). Improving the availability, granularity and accuracy of data is one avenue towards making payment schemes more effective. The same data can also be used to drive quality improvement initiatives at under-performing providers.

Available evidence suggests that, to be effective, outcome-based payment schemes need to provide financial incentives that are of sufficient size to influence provider behaviour; be based on a limited set of mutually coherent and consistent outcome measures to make it clear what matters; be developed through engagement with providers; reward both, achievement and improvement; and offer support for improvement (Damberg et al., 2014^[51]). Finally, it is of crucial importance that outcome measures are risk-adjusted, using methods that distinguish between what providers can influence and the baseline risk of their patients, not to penalise providers that treat more complex patients and to avoid risk selection.

Provider payment models can pose barriers to ICT-enabled services

One of the anticipated effects of ICT in health is the possible replacement of certain activities that are currently performed by medical staff but can be automated, to allow staff to better focus their time with patients (see Chapter 4). While the cost saving-effect is up for debate and investigation, this will significantly change the cost structure of producing health services.

Health services might in the future undergo the same transition as have the markets for encyclopaedias or mail services, reducing marginal unit costs to a minimum and enabling the provision of large service

volumes and increased patient convenience. Many more services will involve fewer hours spent by costly medical staff and be scalable more easily than traditional services. Today's providers of psychological counselling, for example, need to charge a fee close to the cost of providing the human resource. A provider of digital counselling will have close to zero marginal cost of providing the same, but higher development costs.¹²

The ability to produce services at low marginal cost is a challenge for traditional provider payment mechanisms more broadly. Existing payment mechanisms and contractual relationships between payers and providers may vary in their ability to incorporate and promote innovation and the adoption of ICT. For outpatient services, payments are often made on a fee-for-service (FFS) basis, based on a central service nomenclature and fee schedule. ICT can lead to the creation of entirely new services or tools that might not be defined by existing nomenclatures (Gregor-Haack, 2018^[55]), which can lead to difficulties for providers to obtain adequate payment. Because FFS payments also reward providers for the provision of each additional service, they might represent a barrier to the implementation of ICT that requires significant up-front investments before becoming operational. In these cases, providers might refrain from adopting new ways of working and, ultimately, health systems may miss opportunities to adopt new and effective solutions.

In primary care, new digital services can also challenge traditional capitation models, when the geographical location of patients do not fall into the defined catchment areas of providers. Box 8.3 illustrates the concrete challenges for payment policies that need to align with new ways of delivering services in the English primary care system, and how these challenges are met by NHS England and the General Practitioners Committee of the British Medical Association.

Payers can incentivise better care with effective use of data, but some unbundled payments for specific activities may still be needed

To foster the development or delivery of specific services development, payers have in the past often “unbundled” some service components from broader provider payments that can incentivise better integration of services. The goal of such unbundled payments is often to incentivise the adoption and diffusion of new health technology through additional remuneration for selected investments or activities, such as block grants to solve specific problems for which a technical solution is available, or various forms of additional activity-based payments for new digital solutions (OECD, 2017^[56]).

The same approach is often used to encourage specific activities that have proven effective or can increase care quality. For example, since 2018 the US Centers for Medicare & Medicaid Services (CMS) reimburses physicians for collecting and interpreting patient-generated data. In addition, separate payments are available for educating patients to use remote monitoring technology, including at least 20 minutes of staff time per month to interact with patients in relation to remote monitoring. Also with the objective of enhancing quality, the set of monitoring services that attract separate payments might be expanded further (Sweeney, 2018^[57]).

Box 8.3. Adapting the primary care capitation model to meet new forms of service delivery

NHS England is currently updating its contracting and payment rules for primary care funded through capitation, to ensure new technology is safely integrated into health and care pathways while not destabilising existing services. Although still on a relatively small scale, the first provider contact by patients is increasingly made via a digital channel, driven by ICT and data for triage and diagnostics. The current payment system has several characteristics which were implemented to address challenges in traditional primary care, but are now working against the integration of ICT. For example:

- The listed populations of practices have, on average, similar characteristics. This level of homogeneity has made one “standard” payment model possible, which is now challenged. Different patient groups, primarily defined by symptoms and age, are increasingly seeking a different mix of support between ICT-based and face-to-face contacts. They thus effectively demand two rather different types of primary care.
- The design of the current payment system did not anticipate that geographical locations of providers and patients are not relevant for the delivery of digital services. Capitation adjustments, which compensate for higher costs of factor inputs in London, the difficulty of attracting staff, and for making home visits in remote areas, may no longer reflect true differences in the cost of delivering digital services.
- In the past, joining the patient list of a given provider often meant that patients stayed on the list of the same provider for a considerable time, which supports continuity of care. This allowed, for example, for introducing additional incentive payments to encourage prevention for newly-listed patients and payments that value care coordination efforts of primary care services. Early findings from evaluations of digital services show that patients are less faithful to their provider, which can potentially make such payments counter-productive.

To meet these challenges and ensure that available resources are distributed fairly to general practices, a set of changes to the payment system have been presented in the form of an engagement document to the public, primary care professionals and digital innovators. The result will inform the GP contract negotiations for 2019 – 2020 and beyond. It includes limiting the rurality and the London adjustments, and revising first-year-registration payments to mitigate adverse effects. An important forward looking policy is to mandate the reporting of activity and costs of digital provision in general practice to enable close monitoring of the development and continuous development of payment rules.

Source: Based on NHS England (2018^[58]) “Digital-first primary care and its implications for general practice payments”, https://www.engage.england.nhs.uk/survey/digital-first-primary-care/user_uploads/digital-first-access-to-gp-care-engagement-document.pdf.

There are, however, several reasons to be cautious with unbundled payments for new technology. In particular, depending on provider structures and contracting arrangements, there is a risk of further fragmentation of services across providers with increasing fragmentation of payments. Separate service-related payments can hamper integration of services and patient-centeredness. Integrating new ICT solutions into existing provider structures is paramount not only to ensure access to services based on need but also to avoid further fragmentation of service delivery, and attendant fragmentation of data, between providers of *traditional* services and those who provide new and ICT-supported services. In addition, fee-for-service payments incentivise increases in volume rather than service integration, which may drive up total costs.

As stressed on several occasions throughout this report, making the most from digital technology in health and health care requires fundamental re-design of processes, workflows and systems. Cleaving remuneration for ICT adoption away from other aspects of care delivery may provide a disincentive for the institutional transformations that are required.

Payers therefore need to strike a careful balance between activity-based payments that can help adopt certain technologies and broader bundled payments that can provide the right incentives to integrate services and improve health outcomes. Unbundled payments and block grants may remain appropriate to fund specific activities, such as implementing a new ICT tool, especially if new tools or services require large up-front investments while marginal costs of service provision are low. At the same time, payment mechanisms need to move towards incentivising treatment results and value for the patient. Well-designed payment models that factor in outcomes – and, with the help of longitudinal data, over longer time horizons than previously possible – may incentivise provision of the most effective services. Also, the geographical location of providers and the mode of service provision are less relevant if payments can *follow* patients and are based on outcomes achieved (Dinesen et al., 2016^[59]).

8.4. Overcoming historical barriers in health systems can enable progress but risks need to be managed

A number of barriers prevent health systems from realising the potential presented by ICT and data in governance. These are mainly institutional and organisational, including historical health system fragmentation and insufficient standardisation of data. Overcoming these barriers would enable countries to make significant progress. However, governments also need to manage risks to progress, in particular further fragmentation as a result of implementing ICT systems that are not interoperable and the incentive for private owners of data to turn them into commodity and prevent other entities with legitimate interests from accessing and analysing data. This section discusses the main barriers to and enablers of greater use of data in health systems. It also outlines the risk posed by private data ownership.

8.4.1. A number of barriers to greater use of ICT and data need to be overcome

A number of barriers currently impede the greater use of ICT and data for system-level governance. Many of these are a legacy of the historical fragmentation of health systems, which predates the digital era, and a lack of common data systems across provider organisations and payers.

Health system fragmentation and dispersed data challenge the use of ICT and data in governance

Traditional decentralisation – or fragmentation – of most health systems is a particular hurdle to using data for governance, which requires that information systems are integrated and provide comprehensive data on system-wide performance.

This can lead to a vicious cycle: decentralisation is often the historical reason for why ICT systems are not interoperable, while the lack of interoperability can in turn exacerbate fragmentation and silos.

In addition, functions such as regulation, purchasing and quality control are under the responsibilities of different entities in most health systems. Many of these functions are also geographically fragmented, even in single purchaser systems (Kierkegaard, 2015^[60]). In such an environment, scaling up local information systems and proven concepts of performance monitoring can be challenging. For example, in the English NHS, ICT solutions are sometimes implemented differently in separate parts of the system, depending on how local ICT systems are designed and procurement is organised, which can result in need of customised implementations of the same new application (Blackwood, 2018^[61]).

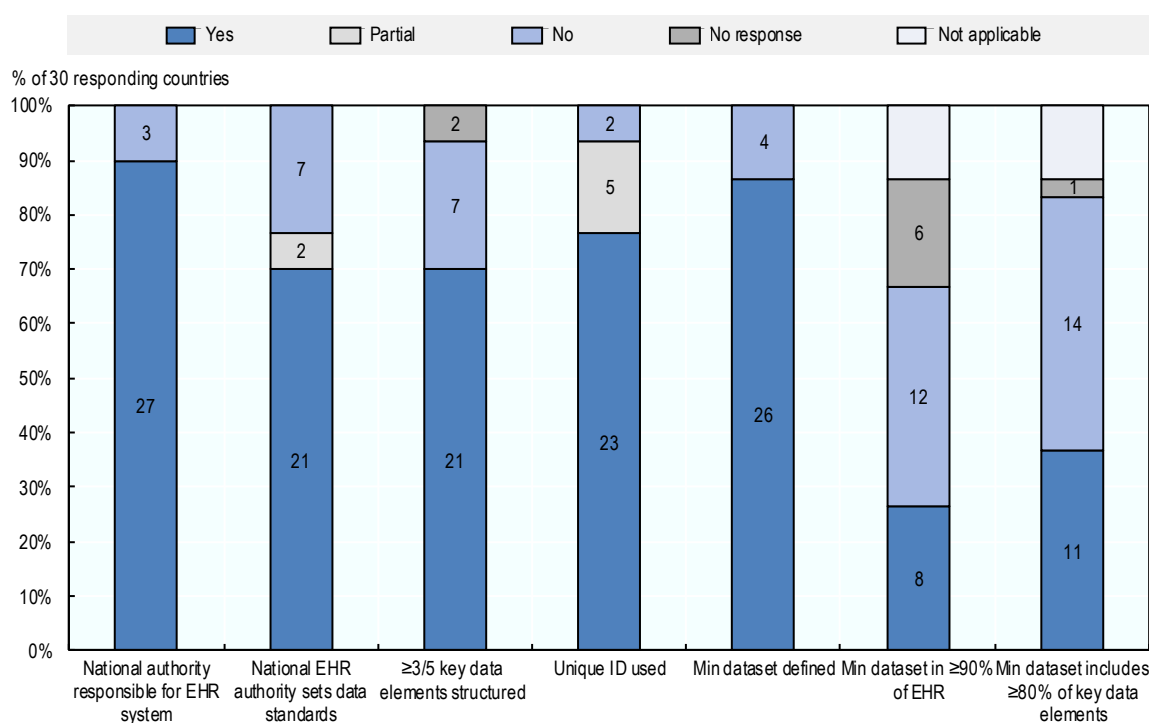
In a way, digitalisation is highlighting longstanding problems and challenges in health systems, such as fragmentation and a lack of institutional alignment and cooperation. But it also presents an opportunity to finally address these. However, while advances in technology can help overcome barriers and integrate care and data systems, there is also a risk that they exacerbate the historical problems. There is indeed a

booming wealth of ICT solutions for clinical care, information sharing and to monitor the consumption and quality of services. But many of these solutions are developed locally as individual providers or payers adopt new ways of working. As shown in Chapter 2 on care models, even successful ICT projects in health care often have problems with scaling up. Bringing individual ICT tools, and the data they generate, together for their use in system governance remains a true challenge that must be tackled by policy makers.

While electronic health records still hold large potential, EHR systems often mirror health system fragmentation

The EHR is a cornerstone of health information systems that allows for secondary use of medical and health data for a range of governance-related purposes. The penetration of EHR in health systems is rising. Of the 30 countries that responded to a 2016 OECD survey, 27 countries (90%) identified a national authority with responsibility for the EHR infrastructure in the country, although in some instances this authority did not have the full responsibility for technical and semantic standards, nor the actual implementation of the system (Figure 8.4).

Figure 8.4. Countries reporting selected characteristics of EHRs



Source: Based on Oderkirk (2017^[62]), "Readiness of Electronic Health Record Systems to Contribute to National Health Information and Research", <http://dx.doi.org/10.1787/9e296bf3-en>.

In recent years, OECD countries have also made progress in implementing unique patient IDs, increasing the analytical utility of data through the ability to link disparate datasets. For example, linkage allows for adding socio-economic data to information on health and service use. In 2016, 23 countries reported the use of a unique ID to allow person-level linkage of data (see Figure 8.4). The ability to connect health data to other data outside the health system varies, however, as this requires that the same IDs be used by other sectors.

However, a prevailing obstacle is, again, that EHR systems often mirror the traditional fragmentation of health systems: countries often have separate EHR systems by levels of care (e.g. one for primary care and another for the hospital sector) or dissimilar systems in different geographical areas, networks of providers or health care organisations. Data thereby become available only to the providers who created them, or group of providers that are part of the same level of care, the same network, or the same geographical area. In addition, primary documentation of care delivery is often subject to the same fragmentation and terminologies, nomenclatures and vocabularies used are frequently proprietary. The process of documentation may also be divided into separate tasks for primary documentation and for secondary reporting, leading to different levels of accuracy, and potentially reduced data quality for secondary use.

Adopting EHRs also does not necessarily create a comprehensive dataset. The 2016 OECD survey found that the national minimum dataset covered 80% or more of the key elements of EHRs¹³ in only eleven countries (37%), including both structured data and unstructured information, such as free-flowing text. Twenty-one countries (70%) reported that three or more of 5 data elements related to diagnoses and treatments were structured, using controlled vocabulary or codes (see Figure 8.4). Greater use of controlled vocabulary or standard terminology would enable more effective use of data for analysis. In Norway, for example, a pilot system of coding and classification of health information is underway to improve the structure of datasets.

Ten countries (33%) reported that there is more than one definition of a minimum dataset in use in their country, leading to data inconsistencies across different parts of the country (Oderkirk, 2017_[62]). This heterogeneity is typically caused by fragmented health systems, in which distinct administrative entities have implemented their own minimum datasets and conform voluntarily to nationally recommended standards. For example, Denmark is relatively advanced in terms of the use of ICT in health care, particularly in direct patient care. Creation of an integrated ICT system, however, is challenged by fragmentation and multiple electronic medical record (EMR) systems. In turn, this hampers secondary use of aggregated data (Kierkegaard, 2015_[60]).

8.4.2. While data are becoming the key input to innovation and can be considered a public good, data often become privately owned commodities

Effective public governance by means of data is also challenged by a trend of data becoming increasingly a 'commodity' in their own right, as they are the key assets of digital businesses and inputs to innovation (OECD, 2019_[8]). As health-related activities generate more and more data that have an analytical use, there are incentives to exploit the commercial value of data and share them only if they are transformed into a product that can be bought and sold on the market. That can imply that private owners of data, entities that aggregate and combine datasets in unique ways and especially providers of sophisticated analyses can extract significant economic value from data by precluding other parties from accessing these data (i.e. creating scarcity). This problem will probably be exacerbated by opportunities in using data from outside the health care sector, such as behavioural data flowing from digital traces people leave in using ICT.

Having data that are not readily accessible is problematic for several reasons. First, governments and other entities responsible for health system governance need access to all data that are relevant to health to generate consolidated and complete information in order to effectively govern the health system. Second, many opportunities are missed when data are not shared, in public policy, health service delivery innovation and private sector product development. Third, data created and stored outside of public entities are often not under public control. Their use does not necessarily serve health policy objectives but rather the interest of private data owners or custodians.

However, the full knowledge-generating potential of data and their value to societies can only be unlocked by making them available to all stakeholders who can turn them into valuable information (OECD, 2019_[8];

OECD, 2019^[63]). Electronic data are non-rivalrous. Their use by someone does not prevent someone else from using them or decrease the utility of their use. Electronic data can also be duplicated and shared across geographic distances at very low marginal costs. Health data can thus be considered a public good and society can benefit from making them available on the broadest possible scale (Grossmann et al., 2010^[64]; OECD, 2019^[8]).

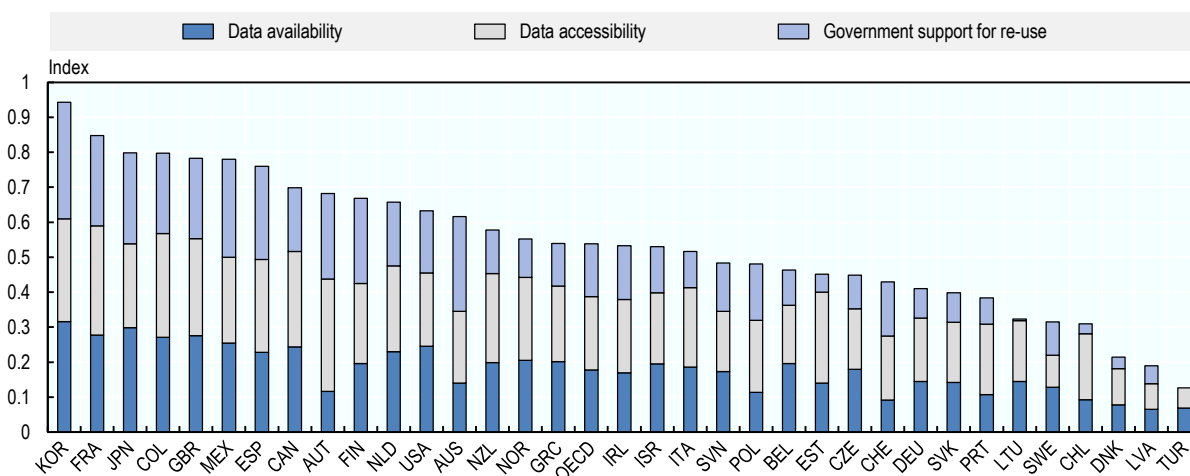
While the adoption of EHRs, the expansion of data collection and interoperability are all important prerequisites, they are only intermediate goals. If data are to improve health system performance, policy must create environments and conditions for effective use of data by all stakeholders, both in service innovation and for system governance (Colclough et al., 2018^[65]). This in turn requires that data are broadly available at low or zero cost for the largest possible group of stakeholders (Sheikh, Sood and Bates, 2015^[66]). Open-access and open-science policies can help turn data into knowledge (OECD, 2019^[8]) To foster innovation, a general principle in policy on data access is that it should (OECD, 2019, p. 14^[63]):

Ensure the broadest possible access to data and knowledge so as to favour competition and innovation, while respecting constraints regarding data privacy, ethical considerations, economic costs and benefits, and intellectual property rights considerations.

This applies to use of data generated in the private sector by public sector entities that make up much of health systems in OECD countries, as well as access to public sector data by private entities that may drive entrepreneurial innovation. In sectors outside of health care, opening public sector data has been shown to catalyse innovation by the private sector (OECD, 2019^[8]). However, the openness of government data varies significantly between OECD countries (Figure 8.5).

Figure 8.5. Openness of government data in OECD countries

Open-Useful-Reusable Government Data Index (OURdata), 2017.



Note: The OURdata indices take values between zero and one, with one being the most open. Each component can score a maximum of 0.33. Source: OECD (2019^[8]), "OECD Going Digital: Shaping Policies, Improving Lives" <https://dx.doi.org/10.1787/9789264312012-en>.

In contrast to data that are generated as a pure by-product of health care delivery or other human activities, access to some specific types of data whose generation entails significant costs, might need to be subject to exclusivity through intellectual property rights. This is an area where policy on intellectual property, that was generally developed for tangible products, may need to evolve to strike the right balance between economic incentives to generate data and the societal benefits of open access to data (OECD, 2019^[8]).

The question of who benefits from secondary use of data also continues to shape debates about the use of ICT in health care and the use of personal data generated within or outside of health systems. People often support data sharing between health care providers involved in their care, but may be less supportive of sharing their health data for secondary uses (Castle-Clarke, 2018^[67]). While surveys suggest that people are generally willing for their data to be used for secondary purposes by not-for profit organisations, academic researchers and government agencies, views are mixed on sharing data with commercial organisations that undertake health-related research (Skovgaard, Wadmann and Hoeyer, 2019^[68]).

A poll in the United Kingdom found that a majority of people aged 45 and older oppose the sharing of their health data for with commercial organisations (Castle-Clarke, 2018^[67]). Also in the United Kingdom, the use of NHS patient data by Google DeepMind has sparked debates about whether private firms should be allowed to access patient data to develop privately-owned technology they can then sell *back* to health systems with a profit motive (NewScientist, 2016^[69]). DeepMind develops machine learning algorithms that can help, for example, predict disease onset. Ownership of data is therefore becoming a crucial question for the ability to govern future health systems. Some countries lead the way through creating large data repositories that allow for central access to a wide range of datasets. While robust data governance is a fundamental prerequisite for greater use of data in governance, this topic is beyond the scope of this Chapter.¹⁴

8.4.3. Making data more widely available could enable progress

National data centres or distributed networks can store and facilitate the use of vast amounts of diverse data

Large data repositories or centralised management of data access and linkage by a public entity can create opportunities for data access by a variety of persons beyond public entities themselves, for use in research, performance monitoring and service development. This can improve access to data for stakeholders with legitimate interests, such as government departments and agencies, research institutions as well as industry. Providing public infrastructure for data storage and maintaining public ownership of data are means of achieving the dual goals of enabling all stakeholders to turn them into valuable information while also keeping data under public control (Salas-Vega, Haimann and Mossialos, 2015^[70]).

Institutional arrangements can be designed in various ways and still meet the same functional purpose of a national data repository. They can, for example, be integrated into public administration, overseen by arms-length bodies or be built on a platform that is separate from government. In addition, all data need not be in the same place. Distributed database networks can enable linkage and integration on a case-by-case basis (e.g. related to a particular research question) while maintaining physical separation, which reduces the risk of compromising entire datasets.

For example, Estonia has established an independent e-governance function that provides a wide range of sectors with a nation-wide and integrated information system.¹⁵ The system integrates data from different health care providers into a common electronic health record (EHR) and can also integrate data from beyond the health system. It combines diagnostic data from tests and imaging, physician visits, inpatient treatments as well as medication prescribed through an e-prescription system. Patients can access their own records through an online patient portal (see Chapter 2 on care models) and, at the same time, the system is the source for a wide range of national statistics.

The backbone of all Estonian e-services, including the e-health services, is the so-called X-Road, an environment that allows the various e-service databases (both in the public and private sector) to be linked. It is thus not a centralised national database, but can integrate data from various sources using different systems and present them in standardised formats. This preserves the ability of individual government agencies, and other entities that use the system and contribute data, to flexibly choose IT solutions that best fit their requirements (European Commission, 2016^[71]).

... increase availability of traditional data...

New integrated data systems also have the potential to merge existing data sources that were previously very cumbersome to combine. Applying new machine learning techniques to EHRs and other health and clinical registries has the potential to decrease the costs and increase the effectiveness of secondary use of data (Bhatt et al., 2015^[72]). In countries such as Denmark, Norway and Sweden, professional associations have for decades developed disease registries that provide long time series of variables defined by clinicians, which are highly valuable for research and monitoring of service quality (Tavazzi and Ventura, 2016^[73]). Shortcomings of such databases are that they are as fragmented as medical practice and that their use is often dependent on significant amounts of manual work (although as outlined above, registries can be constructed virtually from existing routine data e.g. New Zealand).

Norway is a case in point, with a wide range of national health registries that are used for quality improvement, research, administration and emergency preparedness. These registers have contributed considerably to medical advancements and new knowledge. However, researchers and analysts often spend a lot of time obtaining and matching data from different sources. In order to improve access to health data and to facilitate analysis, the Norwegian Directorate of eHealth has established a national health analysis platform with data from health registries, health surveys, national statistics and other relevant sources. When fully implemented by 2020, data will be available for research, health statistics, health care quality improvement, emergency preparedness, health service management and system administration.

Finland has an abundance of high quality data in health as well as social and welfare services but they are dispersed across a number of different information systems and are managed by many different authorities, making secondary use cumbersome and costly. To reduce these barriers, Finland is currently creating a one-stop shop for all secondary use of health and social care data, enabling a wider set of data to be integrated for public use. After the reform, a new agency will have access to an array of data sources and will be the single authority approving all secondary use. The data management reform is complementing the planned health care and social sector reform, which integrates several public administrations across geographical areas and sectors.

A cornerstone of the reform is needs-based resource allocation to local budget holders and performance assessment of providers and budget holders, which requires comprehensive data from both the health and social care sectors. A simplified governance structure will aim to ensure that a single entity is responsible for all health and social care and that care will be integrated between different provider organisations.¹⁶ In addition, the Finnish government anticipates that other sectors can benefit from a secure and user-friendly environment of health, social and wellbeing data, including research and private sector innovation to advance health and wellbeing.

...and integrate wider data sources

Recognising that health care is not the primary contributor to health, but genetic, environmental and behavioural factors indeed have the largest impact, there is great potential in also integrating data from these spheres with health and social care data. This requires, however, that data created (and stored) outside of health systems are made accessible to authorities responsible for health system governance.

The Korean government, for example, aims to integrate the National Health Insurance Database (NHID) with new data sources relevant for public health, such as climate, pollution and spatial network data that captures the movement of people in public spaces. The NHID already covers the entire population and integrates a wide variety of data from electronic health records (EHRs), in addition to insurance claims and health service activities. The latter includes data from services for individual health promotion, screening, curative care and rehabilitation. A unique personal ID assigned to every citizen at birth supports data linkage between health insurance data and other databases. Analyses are made available to inform public

policies, disease monitoring and clinical practice guidelines. So far, analytical uses of the NHID have included, for example (WHO, 2017^[74]):

- Identifying causality and predicting risk by linking health-screening data with medical history and socioeconomic status.
- Creating an evidence base on health risks and diseases by region and workplace to develop customised health services in communities and workplaces.
- Developing a surveillance system to target chronic diseases, based on information of service use by patients with chronic diseases.

New data collection and extraction techniques enable the secondary use of data from a wider range of sources. With a distributed data infrastructure, the US Food and Drug Administration (FDA) has developed Sentinel, a system that can access a range of data sources including EHRs and insurance claims to monitor safety of medical products after marketing authorisation. The system automatically extracts and centralises relevant information from a wide set of partner organisations in the health system that serve as data sources. Prior to Sentinel, FDA worked with one data source at a time, analysing, for example, claims data from a specific insurance scheme. With Sentinel, FDA can instead rapidly access electronic data from almost 200 million patients. This way FDA can proactively assess the safety of regulated medical products, as opposed to the traditional reactive surveillance approach (FDA, 2018^[75]).

8.4.4. More ICT and more data will not drive transformation without leadership and capacity

This section has described a number of barriers to as well as opportunities for greater use of data in health system governance. It highlights the growing strategic focus in a small number of countries on putting the growing volume of data in health systems to better use for such purposes. It shows the benefits of making the wealth of data available to all stakeholders as a public good but also how health systems still lag behind as a result of fragmentation and a lack of data standards.

However, being able to use data for more effective governance is not only about sophisticated data collection, storage and linkage systems. Neither is it only about harnessing new types of data. Putting data to use is equally reliant on the ability to generate actionable knowledge as well as political will and capacity to take action based on this knowledge. Health data collected for other primary purposes, e.g. activity data for insurance reimbursement or prescription data for quality assurance, have been available for decades but not always used for secondary purposes. For example, the OECD review of the Latvian health system found that the country is underusing its data-rich environment. A wealth of data is traditionally collected, but proper analytical and evaluating functions could be used much more actively in governance (OECD, 2016^[76]). Section 8.5 discusses how countries could make progress.

8.5. Countries can progress on various fronts to harness data for better health system governance

Just as governance is a means to attain policy objectives, ICT and data can be very effective *means of* governance. Sophisticated use of data is not the ultimate goal in itself. To support development of useful ICT and move towards more effective use of data for health system governance (and indeed other secondary purposes), governments have to advance along several avenues simultaneously.

Most directly, governments, government agencies and other relevant entities need to advance their use of data to make governance a more effective means of achieving policy objectives, including resource allocation that is conducive to achieving these objectives. At the same time, they have the more traditional role of steering and regulating the market that develops health-related ICT in a way that ensures security,

integrity and collective utility (e.g. interoperability) of technologies. They also need to create an environment in which health care providers use the right technologies that improve service delivery and produce data that has secondary utility. This entails encouraging the right innovation in ICT and in health service delivery, and minimising any disincentives for this to happen.

This section outlines some possible avenues governments could pursue to advance their ability to harness data for health system governance. It discusses three main ways through which governments could enhance their capacity to use ICT and electronic data for system governance:

1. Adopting inter-sectoral strategies that guide stakeholders in the development and adoption of ICT, including a more strategic approach to creating incentives for the ICT industry;
2. Instituting health data governance frameworks and infrastructure; and
3. Developing policy and managerial capacity to not only generate knowledge from data but also to deploy this knowledge to achieve better policy outcomes.

8.5.1. System-level strategies can guide the development and use of ICT and can serve governance objectives in and beyond the health system

Effective use of data and digital technologies for governance requires that the right ICT solutions be available, that individual administrative entities, payers and providers adopt interoperable systems and shared data standards and that data be accessible for governance and all stakeholders with legitimate interests.

Comprehensive digital health strategies are an important means to achieving coherence across the health system, which can ultimately improve the use of ICT and data for governance purposes. A key advantage of an overall strategy is that it can guide the creation of a common ICT framework and infrastructure (discussed next) and guide technical requirements to ensure that individual solutions, which will likely be developed locally and on a small scale first, are interoperable and coherent with the architecture of an overall ICT system. Strategies can also set priorities in terms of access to technology and identify disadvantaged population groups that require specific support to reap the benefits of ICT, which helps achieve equitable access to new types of services. Finally, strategies can establish an integrated governance framework that involves all stakeholders, including the technology industry, and encourages cooperation in developing the right solutions.

In recent years, recognition of the importance of comprehensive national strategies to guide the future of ICT and data has increased. The 2015 Global Observatory for eHealth survey showed that 66% of 125 responding countries had adopted a wider national health information system policy or strategy, of which most countries (58%) also had a specific e-health strategy to guide digital health services (WHO, 2016^[77]). In the same survey, 90% of countries with an e-health strategy made reference to health system objectives these strategies aimed to support, like universal health coverage or its key elements. A common starting point is strengthening of individuals' ability to take part in their health decisions, in terms of both health promotion, illness prevention, and curative care.

Many OECD countries have defined system-level e-health strategies or similar guiding principles. Among the 15 countries that responded to the survey conducted in research for this report, 11 (73%) referred to a strategy in their responses. However, only six countries (40%) stated that they also had a health data strategy that guides the use of data for system-level activities related to governance.

In Canada, where health care is a decentralised responsibility of provinces and territories, health-related ICT has been made a shared priority between the federal and provincial governments. The federal government established Canada Health Infoway, an independent and not-for-profit organisation in 2001, to advance a pan-Canadian approach to health-related ICT and promote the implementation of a common

digital architecture. Both, federal and provincial health ministries are part of the Canada Health Infoway governance framework and define priorities jointly.

Beyond the health system, digital strategies also aim at linking and increasing the use of data to achieve wider goals, such as greater social inclusion and the ability to identify and meet the needs of disadvantaged groups. In Israel, for example, the need for a digital strategy to guide all government policy was recognised in 2013. The ensuing National Digital Program currently guides government policy for the years 2017-20. It has three overarching objectives: reducing socio-economic gaps; accelerating economic growth and promoting citizen-friendly 'smart' government (Israel Ministry for Social Equality, 2017^[78]). The strategy spans all domains of government policy, including health, and is implemented along five cross-cutting areas: technological infrastructure; realising citizens' rights; procurement; regulation and building of human capital (ibid.). Implementation is overseen by the Ministry for Social Equality. In parallel, the Ministry of Health has adopted its national digital health strategy to guide actors in the health system as well as all other stakeholders, including academic researchers and innovative start-ups in the private business sector, in not only harnessing digital technology to improve health but also to make digital health a source of economic growth. Funding of nearly ILS 1 billion (about USD 276 million) is being made available over 5 years for pilot projects, research, and the improvement of information infrastructure. Notably, the strategy is also accompanied by reforms of regulations and data governance to facilitate the secondary use of health data for purposes of public benefit.

The Swedish e-health strategy (see Box 8.4) illustrates the broad context of social inclusion and inter-sector dependency. The strategy builds on earlier progress in e-governance of other sectors, which has improved significantly the communication between government entities and citizens and the responsiveness of such entities.

Box 8.4. The Swedish e-Health strategy

The Swedish Government and the Swedish Association of Local Authorities and Regions have jointly developed and endorsed a strategy for eHealth called *Vision for eHealth 2025*. It rests on a bold vision statement:

In 2025, Sweden will be best in the world at using the opportunities offered by digitisation and e-health to make it easier for people to achieve good and equal health and welfare, and to develop and strengthen their own resources for increased independence and participation in the life of society.

Individual participation in health is a focus. The starting point for the strategy is the radical shift seen in several other service industries, such as travel and banking, where the meeting between providers and clients has shifted to a digital interface, fundamentally changing who does what, the volume of data generated in the process and how these data are used. Equally important is the general e-governance system that has changed many parts of government-citizen relationship in the last decade, while the health sector has large potential unfilled in this area.

The strategy includes several guiding principles. Digitisation shall mitigate the traditional fragmentation in health and social services by integrating data from both sectors to support seamless care pathways and integrate services. It shall be a tool to target marginalised and underserved groups, avoiding that gains from digitisation only benefit affluent population groups with better digital literacy. It shall strengthen monitoring of unjustified differences between outcomes in different services and population groups.

The implementation of the strategy is based on three pillars and outlines the division of responsibilities between the central government and local authorities.

- Pillar 1 aims to maximise information exchange, both between different public authorities and with citizens, while safeguarding privacy and data security.
- Pillar 2 aims to advance the semantic interoperability of data within the health system.
- Pillar 3 focuses on technical interoperability, and therefore relies on global technical standards, particularly for a small country.

Together, these three pillars provide social support and care providers, payers of health and social services, and monitoring functions, such as government analysts and researchers, with access to a broader dataset at the individual and population level and across administrative levels. This will increase the ability to better identify unmet need and provide comprehensive services across health and other sectors. It will also support attainment of the specific objective to increase effectiveness in communication with people and patients by integrating available information in all communication channels, which has been key to success of general e-governance.

Source: Based on Government Offices of Sweden (2016^[79]). "Vision for eHealth 2025", <https://www.government.se/information-material/2016/08/vision-for-ehealth-2025/>.

8.5.2. Instituting health data governance frameworks and infrastructure

Health data governance and appropriate data infrastructure are the socio-technical backbone of knowledge-based health systems, and indeed the key to realising a digital transformation more broadly. While infrastructure provides the technical basis for collecting, storing and analysing data to generate insights, sound data governance ensures that this is only done in the best interest of citizens and helps build greater trust. Although the delivery of health care is a highly knowledge-intensive activity, health systems still invest very little in systems that create knowledge from available data.

Sound data governance can enable secure use of data and build trust

Governments therefore need to spur investment in information systems that are interoperable and put in place a legal framework that enables their use while ensuring privacy and security. Through the OECD Council Recommendation on Health Data Governance, OECD countries agreed that governments should (OECD, 2019^[80]):

Establish and implement a national health data governance framework to encourage the availability and use of personal health data to serve health related public interest purposes while promoting the protection of privacy, personal health data and data security.

To achieve this goal, the Recommendation sets out twelve principles that can be grouped into technical, policy and communication categories (ibid.).

Sound data governance is needed for establishing trust. Lack of trust among patients, the public, data custodians and other stakeholders in how data are used and protected is a major impediment to getting more out of data. Personal health data are very sensitive, and privacy is understandably one of the most frequently cited barriers to using them. But by generating useful knowledge, using personal health data can also make a great contribution to overall human health and welfare. As discussed in Section 8.4.2, people are often positively disposed to their data being used as long as the data are kept secure and are used for purposes that benefit society.

Estonia, for example, has developed a comprehensive e-government framework that makes nearly all government services available online. The framework includes health services. The backbone of e-government in Estonia is the aforementioned X-Road, a data exchange layer for information systems that allows distinct entities, including all government departments and agencies across different sectors, to

exchange data efficiently and query distinct databases according to their legitimate needs. The environment also ensures data security through user authentication, multi-level authorisation requirements, encryption of data and logging of all data traffic through a multi-tier method that includes blockchain technology (see Box 2.2. in Chapter 2 on new care models). Based on the United Nations e-Government Survey, Estonia is among the highest scorers in terms e-government development and cybersecurity (UN Department of Economic and Social Affairs, 2018^[81]). Yet, even in Estonia, making effective secondary use of the data available remains a challenge.

Implementing the OECD Council Recommendation will address many of the barriers of using data and putting them to work for positive system transformation. For example, it provides a clear structure for leaders to communicate the benefits of using data and enabling public discourse to encompass opportunities as well as risks. It also dispels the notion of a trade-off between data protection and their use. Crucially, governments adopt common policies that minimise barriers to sharing data for legitimate purposes that serve the public interest, including health system management.

Results from a 2019 survey that monitors implementation of the Council Recommendation indicates that about two-thirds of OECD countries that responded to the survey have already established or are establishing a national health data governance framework.

Continued focus on data standards and new analytical methods are needed

Solving the lack of interoperability, a fundamental obstacle in data management, has great potential to catalyse the secondary use of health data (Wachter and Howell, 2018^[82]). This will in turn increase governments' ability to use ICT and data for governance.

In addition to other technical requirements, data standards can help overcome decentralised and fragmented systems. National standards can guide ICT developers as well as providers and payers in developing and implementing systems that are interoperable and adhere to common minimum dataset specifications.

Established in the United States by the HITECH Act in 2009, the US Centers for Medicare and Medicaid Services (CMS) EHR Incentive Programs, for example, provided incentives for health care providers to adopt, implement, or upgrade to certified EHR technology and to meaningfully use EHRs to improve care coordination and quality. The Office of the National Coordinator for Health Information Technology (ONC) adopted standards and established criteria for the certification of health IT. In the CMS programs, hospitals and physicians are required to report on the specific measures of use of certified EHRs, related to, for example, e-prescribing, care coordination, public health reporting, quality metrics and patient engagement. The proportion of office-based physicians in the United States that used EHRs increased from 57% in 2011 to 86% in 2017; 80% of physicians used an EHR system that was certified to meet the requirements by the US Department of Health and Human Services (US HHS, 2017^[83]).

This programme was also estimated to have helped identify more than half a million additional patients with hypertension (Million Hearts, 2017^[84]). This serves as a useful example of a nationally coordinated program that enables the adoption of common data standards across a fragmented system of providers and specialties.

Policy should also guide the ICT industry

The ICT sector is an industry driven by engineers, entrepreneurs and commercial organisations rather than by governments and public policy. Arguably, innovation in ICT-based health services is often driven by unpredictable advances in technology and in changes to local models of service provision, but not necessarily by policy objectives like equity of access and health system efficiency.

In addition to making the best use of the opportunities ICT creates for governance, policy needs to create a framework that steers the ICT industry to produce tools that are conducive to improving health system governance and to achievement of policy goals. This means that governments also have the crucial role of regulating ICT and, through setting requirements and strategic purchasing, creating incentives for private firms to develop the right solutions. While regulation is important to ensure, for example, data security and privacy, sufficient freedom must be given to a vibrant and entrepreneurial sector for it to continue finding creative solutions to complex health-related problems.

So-called regulatory “sandboxes” represent one approach to digital innovation based on flexible application or enforcement of policies, including limited forms of regulatory waiver or flexibility for firms to test new solutions while maintaining overarching regulatory objectives (OECD, 2019^[8]). This approach has emerged in a number of sectors including health but also, for example, in finance, transport, aviation and energy (ibid.). Regulatory sandboxes are typically applied on a case-by-case basis (ibid.).

Largely because of the way new technical solutions are developed in local trial-and-error, but partly also because of health system fragmentation, many projects that make more use of data and ICT focus on solving a single problem at the time. Individual initiatives are rarely designed with the objective of serving the wider health system. More common are attempts to address the needs of a specific patient group, of people with a specific disease or of an administrative entity, such as a devolved payer or regional health authority. As a result, solutions are often developed and implemented on closed platforms, such as a specific hardware or software customised to the problem, creating distinct systems that are not easily integrated. This makes dissemination and scaling of successful new solutions difficult. It can also cause issues with interoperability and imply that data generated by distinct ICT solutions cannot be integrated with data generated elsewhere, which makes secondary use of data for governance difficult.

To use data for governing the health systems, countries also need to effectively govern the ICT that generates data. While the nature of innovation, including the *single problem*-approach and a need for diversity in creative ideas, is not likely to change, countries can do more to manage innovation. This includes the definition of technical standards, implementing assessment processes and tools for choosing ICT solutions and increasing information sharing opportunities.

As discussed above, comprehensive data standards and interoperability requirements as a condition for adoption of ICT by public payers and providers are one building block of such a framework that can help making data suitable for health system governance. Similar to using HTA for other types of health technologies, rigorous evaluation of new ICT, coupled with targeted investment in effective technology and disinvestment from ineffective technology, can create the right incentives for private firms. Such evaluations need to determine the ability of technologies to contribute to achievement of health system goals and to generate data that can be used for governance. Strategic purchasing of ICT by public entities can be one way of ensuring that data standards and interoperability requirements are adhered to and that ICT systems are only selected for large-scale implementation once they have proven effective. The Israeli government, for example, has opened so-called *challenge tenders* to fund, implement and evaluate innovative ICT solutions in health care. These tenders serve the dual objective of ensuring that solutions meet the requirements of the existing ICT infrastructure and that technology firms have sufficient flexibility to find creative solutions. A more detailed description of challenge tenders is provided in Chapter 2.

8.5.3. Building policy capacity

Finally, countries need to invest significantly in building capacity in health systems to identify issues that can be solved and processes that can be improved by using data, to generate data-driven insights and to act upon these analyses. While a strategy that ensures coherence of individual projects, data infrastructure and sound data governance are all prerequisites, only sufficient capacity for analysis and for implementation of knowledge-based change can ultimately improve people’s lives. This essential part of harnessing data for improvement is often overlooked.

Policy capacity refers to the “*sum of competencies, resources and experiences that governments and public agencies use to identify, formulate and evaluate solutions to public problems*” (Forest et al., 2015^[85]). Building such capacity requires financial investment in personnel and analytical resources and ensuring organisational continuity so that successive cycles of improvement can be executed (refer to Figure 7.2 in Chapter 7).

A recent review of the National Health Service (NHS) in England concluded that, despite the vast amounts of data that are available from routine sources, there is a shortage of skills and tools to do analysis and not enough analysts who can collaborate with clinicians and managers to gain insights and translate them into innovation (Bardsley, Steventon and Fothergill, 2019^[86]). Small-scale initiatives at individual provider and payer organisations across England, however, also demonstrate how investment in analytical and translational capacity can improve resource allocation, make care more effective, and deliver improved health outcomes to patients (ibid.).

Improving policy capacity in health systems does not require educating every decision-maker to become a policy or data analyst (Forest et al., 2015^[85]). Rather, it requires building a core workforce among entities that govern health systems that is skilled in economic and social data analysis, operational research, project management and communication skills, combined with a sound understanding of the factors that shape population, community, and individual health, including medicine (ibid.).

Countries also need to equip entities that govern health systems with the necessary policy ‘teeth’ to act on knowledge generated from data. The roles, responsibilities and powers of regulators, payers, public health authorities and other actors in health system governance must be aligned with what data- and knowledge-driven decision making can do.

While more and more targeted investment is needed in information infrastructure, investment should be principally targeted at institutional and policy reforms, skills and expertise. This is because the majority of the costs of implementing data-driven innovations and digital technologies in the health sector are caused by planning, making available the needed human resources and redesigning processes. Capital expenditure can amount to only about a quarter of the overall implementation costs, most of which are related to planning, personnel and operations. More importantly, the initial costs of implementing digital platforms dwarf ongoing, marginal costs of maintenance, which can be as low as 3.5% of the initial costs (Fleming et al., 2011^[87]). Well established findings on the role of digital technology in productivity highlight the dominance of costs related to capacity-building and workflow redesign (Brynjolfsson and Hitt, 1998^[88]).

8.6. Conclusion

This chapter identifies several ways in which electronic data and ICT could be harnessed to improve the governance of health systems to help achieve their overarching goals. It shows how digital technology can be used to identify need for health care with much greater precision, to monitor and improve care quality, to assess effectiveness and costs of interventions to identify waste and improve efficiency. All of this can guide resource allocation within a health system, including provider payment.

However, the health sector is arguably decades behind other industries in terms of realising the benefits of the digital transformation. This represents a considerable amount of resources wasted and health benefits foregone. While the health sector invests a similar share of its resources in ICT hardware, it invests much less than other knowledge-intensive industries, such as education and finance, in software, ICT services and capacity to make effective use of data. The sluggishness of change in the health sector is in stark contrast to industries that have reinvented themselves as digital technology has become ubiquitous to better serve their customers and remain profitable.

While the technologies for making progress are available, institutional and organisational barriers prevent health systems from realising the potential of ICT and data for governance. These include historical health

system fragmentation, organisational and budgetary silos and insufficient standardisation of information systems and data. Overcoming these issues would enable countries to make significant progress.

However, risks also need to be managed. While digitalisation makes long-standing issues of fragmentation more apparent and can catalyse reforms, it can also lead to further fragmentation as a result of implementing ICT systems that are not interoperable. Policy also needs to constrain the incentives for private owners of data to turn them into a scarce commodity and prevent other entities with legitimate interests from accessing and analysing data.

Countries can advance along several possible avenues to improve their ability to harness data for health system governance. Comprehensive and inter-sectoral strategies can guide stakeholders in the development and adoption of ICT, including a more strategic approach to creating incentives for the ICT industry. They can institute health data governance frameworks and infrastructure to make data readily available for legitimate purposes while protecting privacy. Finally, they need to invest heavily in the development of policy and managerial capacity to not only generate knowledge from data but also to deploy this knowledge to improve health system performance.

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Notes

¹ Health data governance is not the focus of this chapter, although it emerges as a key foundational requirement of using data and ICTs for purposes such as those examined in this chapter and the remainder of the report. Section 8.5.2 provides a brief discussion of health data governance in the context of this chapter. For more detailed description and discussion see, for example, OECD (2015^[31]; 2019^[80]).

² For similar and alternative definitions of equity, also see Culyer AJ (2015) Efficiency, equity and equality in health and health care, CHE Research Paper no. 120, Centre for Health Economics, University of York.

³ Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation). <http://data.europa.eu/eli/reg/2016/679/oj>.

⁴ Direct costs of implementing GMA across 13 Spanish regions were in the same order of magnitude as license fees for other risk stratification tools paid by regions that do not use GMA. For example, fees for the Adjusted Clinical Groups (ACG) system were about EUR 350,000 respectively in Andalusia and in the Basque Country (Comunidad Autónoma De Andalucía, 2017^[90]; OSAKIDETZA - Servicio Vasco de Salud, 2018^[91]). In contrast to the GMA system, use of which is not subject to license fees, however, licenses are valid for a limited period of time – for example three years in the Basque Country. Andalusia and the Basque country have populations of approximately 8.4 and 2.2 million respectively while GMA already covers a population of 38 million (see Box 8.1).

⁵ See <https://www.safetyandquality.gov.au/atlas/>.

⁶ See <https://fingertips.phe.org.uk/profile/atlas-of-variation>.

⁷ See <https://www.dartmouthatlas.org/>.

⁸ See <https://www.myhospitals.gov.au/>.

⁹ See <https://www.haigekassa.ee/partnerile/tervishoiuteenuste-kvaliteet/ravikvaliteedi-aruanded#tab-2017> for indicators published since 2015.

¹⁰ Although, as illustrated by the previous Spanish GMA example, these investments can sometimes be relatively economical and need not 'break the bank'.

¹¹ See CMS Medicare Learning Network (2017^[89]) for the full list of indicators and further information on the payment scheme.

¹² The development costs would include the training of the professionals who develop – or contribute towards developing – the digital application.

¹³ Key elements investigated were a unique patient identifier, a unique health care provider identifier, patient demographics, patient socio- economic data, patient current medications, patient clinically relevant diagnostic concerns, patient clinically relevant procedures, patient clinically relevant physical characteristics, patient clinically relevant behaviours, and patient clinically relevant psychosocial or cultural issues.

¹⁴ Readers may refer to the OECD report titled *Health Data Governance: Privacy, Monitoring and Research* (OECD, 2015^[31]).

¹⁵ See <https://e-estonia.com>.

¹⁶ See <https://alueuudistus.fi/en/social-welfare-and-health-care-reform/about-the-reform>.



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