OECD Health Policy Studies

Health in the 21st Century

PUTTING DATA TO WORK FOR STRONGER HEALTH SYSTEMS

OECD

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Foreword

In the past thirty years, digital technology has transformed entire societies and the global economy. The extent of this transformation can be compared to previous industrial revolutions.

The essential element of digital transformation is not smartphones, software, or even the internet. It is electronic data. Digital technology is a way of creating, managing, sharing and analysing data to provide the right information to the right person at the right time. Its inherent qualities mean that this can be done extremely quickly, efficiently and at very low incremental cost. Unsurprisingly, a wide range of sectors have harnessed these unique characteristics to transform their business practices, delivering considerable consumer surpluses and social dividends.

But two decades into the 21st century, and a similar transformation is yet to occur in health. Despite rapid digitalisation and immense opportunities in an industry where information and communication are so intrinsic to success and failure, the health sector remains 'data rich but information poor'.

This report examines how OECD countries are leveraging data and digital technologies to achieve their health policy objectives, and how a digital transformation can help to address existing and emerging policy challenges. It continues a work programme that began in 2010, when Health Ministers asked the OECD to examine how electronic data can be put to work to improve health services, research and policy making. This work has produced several reports, culminating in the *Recommendation of the OECD Council on Health Data Governance*. Health Ministers welcomed the Recommendation at their subsequent meeting in 2017, where they also instructed the OECD to continue examining this topic with a focus on identifying the key barriers and enablers of a digital transformation in health.

The report finds that despite some promising signs and isolated successes, health is a long way behind other sectors. While a digital transformation is not an end in itself, it provides clear opportunities to build effective, equitable, people-centred and efficient health systems. These opportunities are currently being wasted. The report emphasises that a digital transformation does not happen spontaneously. It relies on fundamental organisational change. In health, this means overhauling the structures, policies and institutions that govern how systems function. These institutions pre-date the digital era and are notoriously resistant to change. In some ways, the arrival of digital technology has served to highlight the same problems that have stood in the way of meaningful reform for a long time.

A digital transformation is a therefore a political choice. It relies on leadership and bold policy decisions. It requires investment that, if targeted well, can deliver considerable returns. Above all, it is an opportunity to finally address several fundamental and long-standing deficiencies in the health sector, and bring health into the 21st century for the benefit individuals, communities and societies.

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Acronyms and abbreviations

ACA	Affordable Care Act
AI	Artificial Intelligence
API	Application Programming Interface
BBMRI	Biobanking and Biomolecular Resources Research Infrastructure
CABG	Coronary artery bypass grafting
CDC	Centers for Disease Control and Prevention (US)
CEPHOS-link	Comparative Effectiveness Research on Psychiatric Hospitalisation by Record Linkage of Large Administrative Data Sets
CHF	Congestive heart failure
COPD	Chronic obstructive pulmonary disease
CPD	Continuous professional development
CMS	Centers for Medicare and Medicaid Services (US)
CVD	Cardiovascular diseases
DTC	Direct-to-consumer
EC	European Commission
EEA	European Economic Area
EHDEN	European Health Data and Evidence Network
EHR	Electronic health record
EMR	Electronic medical record
ERIC	European Research Infrastructure Consortium
ECIS	European Cancer Information System
EU	European Union
EUR	Euro
FDA	Food and Drug Administration
FFS	Fee-for-service
FHIR	Fast Healthcare Interoperability Resources
GA4GH	Global Alliance for Genomics and Health
GBP	Great Britain Pounds
GDP	Gross domestic product
GDPR	General Data Protection Regulation
GFCF	Gross fixed capital formation
GFT	Google flu trends
GMA	*Grupo de Morbilidad Ajustado* (Morbidity-adjusted groupiong)
GP	General practitioner
HBM4EU	European Human Biomonitoring Initiative
HCH	Health Care Home
HITECH Act	Health Information Technology for Economic and Clinical Health Act
HIPAA Act	Health Insurance Portability and Accountability Act
HTA	Health technology assessment
IARC	International Agency for Research on Cancer
ICD	International Classification of Diseases

ICT	Information and communication technology
ICHOM	International Consortium for Health Outcomes Measurement
IHME	Institute for Health Metrics and Evaluation
IMG	Integrated Medical Group
IMI	Innovative Medicines Initiative
InfAct	Joint Action on Health Information
IoT	Internet of Things
INCF	International Neuro-informatics Coordinating Facility
IP	Internet protocol
IT	Information technology
NCD	Non-communicable disease
NHID	National health insurance database (Korea)
NICE	National Institute for Health and Care Excellence
NIH	National Institutes of Health
NHS	National health service (UK)
OECD	Organisation for Economic Co-operation and Development
ONC	Office of the National Coordinator for Health IT
PCI	Percutaneous coronary intervention
PIAAC	Programme for the International Assessment of Adult Competencies
PPI	Proton pump inhibitors
RCT	Randomised controlled trial
R&D	Research and development
RWE	Real-world evidence
RWD	Real-world data
SALAR	Swedish Association of Local Authorities and Regions
SaMD	Software as a medical device
SES	Socio-economic status
TEFCA	Trusted Exchange Framework and Common Agreement
UK	United Kingdom
UN	United Nations
US	United States
USD	United States Dollars
WAHCA	Washington State Health Care Authority
WHO	World Health Organization

Executive summary

Health lags far behind other sectors in harnessing the potential of data and digital technology, missing the opportunity to save a significant number of lives and billions of dollars.

A digital transformation is urgently needed and long overdue at a time of increasing pressure on health systems and budgets. This means ensuring access to the right information by the right people at the right time. The results will be safer, better and more efficient health systems and healthier populations.

Building people-centred, efficient and sustainable health systems

A digital transformation can help meet the changing needs of patients and the public. It can serve as a catalyst for a team-based approach to deliver quality and co-ordinated health services. This is particularly important with ageing populations, a growing chronic disease burden and rising expenditure.

People want to take greater control of their health. In 2017, 3.7 billion health-related smartphone apps were downloaded globally, up from 1.7 billion in 2013. The proportion of adults seeking health information online more than doubled between 2007 and 2017.

But while the majority of OECD countries (70%) say they are implementing ways for people to access their heath data electronically, fewer than half (43%) include the ability for patients to interact with their own health records. In addition, such facilities are under-used by those who stand to benefit the most from them.

Intelligent use of data and digital technology improves the safety and quality of care, helps address unmet health need and makes accessing services easier. It supports more informed health system stewardship and policy making. It also assists researchers to develop safer and better treatments, and enables more effective disease prevention and public health, resulting in healthier and more productive populations.

Health systems are plagued by a significant waste of resources. Unnecessary practices, duplication and other inefficiencies mean that around a fifth of health care expenditure in OECD countries (around USD 1.3 trillion annually) is not used to generate better health, and sometimes even harms health. A digital transformation also offers ways to reduce this waste, improving health, saving money and freeing up resources towards more productive ends.

Health can learn from how other sectors were transformed

Other sectors such as education, banking and finance, the media and aviation have been far better at harnessing the opportunities of digital technology to deliver improvements, efficiencies and consumer surpluses.

The transformation in these sectors did not come about by simply digitising existing practices. It required an overhaul of organisational structures, business models and institutions. It relied on fundamental changes to cultures, habits and attitudes. Reform on this scale also needed considerable investment.

In contrast, health systems remain 'data rich but information poor'. Many opportunities to improve the health of individuals and communities remain untapped. The available data and technologies are sufficient, but are insufficiently implemented and used. This is primarily a legacy of institutions, forged in the pre-digital era, that are static and resistant to change. The potential of digital technology has, in fact, highlighted the need to urgently address some long-standing problems such as fragmentation and silo mentality, which get in the way of important reforms.

Investment plays an important role. Countries typically spend less than 5% of health budgets on managing data and information – a much smaller share than other sectors, and paltry for an industry where accurate, reliable and timely information is so critical to success.

As it stands, only a minority of OECD countries are establishing the requirements for digital transformation of their health systems. Denmark, Estonia, Finland, Israel, Lithuania, New Zealand, Norway and Sweden, for example, are making good progress. However, even the frontrunners have a long way to go. Systematic re-purposing of routine data for analysis and knowledge-creation, in particular, remain a major challenge.

A digital transformation requires policy action and leadership

The main barriers to building digital health systems of the 21st century are not technological. They are institutional and organisational. Progress depends on an enabling policy environment. This means resolute action by governments on three main fronts:

1. *An overarching digital strategy*. All countries that are on track to harness the opportunities of digitalisation have this in common. While strategies are many, few are comprehensive and include a consolidated vision, plan and policy framework. Ideally, a strategy will also align with a broader, cross-sectoral digital strategy.
2. *Strengthening governance of health data.* Governance enables data and digital technologies to be put to productive use, while ensuring security and respect for individual privacy. Legal barriers and a lack of trust among patients, the public, data custodians and other stakeholders in the use and protection of data are all major hindrances, as is the lack of agreement on data standards and exchange formats both within and across countries. The *Recommendation of the OECD Council on Health Data Governance*, welcomed by Health Ministers in 2017, sets out the mechanisms to achieve these requirements.
3. *Building institutional and operational capacity*. This includes equipping and preparing the workforce to harness the opportunities of digital technology. It includes empowering the public – especially people with complex needs – to take advantage. It also means putting in place the systems and institutional arrangements that enable efficient linkage and analysis of data. This requires an enabling policy environment so that key actors can not only access data and extract knowledge from them, but can then use this knowledge to effect change and advance policy objectives.

A digital transformation is a complex, system-wide change that requires leadership as well as sustained investment. However, investment need not be in hardware or infrastructure. The most pressing areas include building human capital and expertise, adapting processes and workflows, and modernising policy and governance frameworks. It also means reshaping fundamental policy settings such as payment models, which influence incentives and behaviour across a health system.

Increasing, and in some cases simply re-orienting, current levels of resources to these areas will pay off. The direct health and economic benefits of a digital transformation across OECD health systems would approach USD 600 billion annually – roughly the Gross Domestic Product (GDP) of Poland and around 8% of OECD health expenditure. Even doubling what health systems currently invest in managing data and information would still deliver a three-fold return.

Digital transformation offers great opportunities to build highly effective, efficient and people-centred health systems. Grasping these opportunities requires strong political will and bold policies. Further delay is costly for both health outcomes and health budgets. It is time to bring health into the 21st century.

1 Bringing health into the 21st century

Luke Slawomirski

This chapter provides the key findings and overarching themes of the entire report *Health in the 21st Century: Putting data to work for stronger health systems,* which explores how digital technologies – and especially electronic data, can be put to work with the goal of effecting positive health system transformation. This question is approached from several perspectives: improving health service delivery models, empowering patients and health system users, readying the health workforce to make the most of digital technologies such as artificial intelligence (AI), using big data in public health policy, the importance of cross-border collaboration, using routine and real-world data to generate evidence on treatments and therapies, and improving overall health system governance and stewardship. The overarching messages from these studies are outlined here. The chapter also provides an estimate of the potential health and economic return of investing in a digital transformation of the health sector in OECD countries.

1.1. Introduction

Digital technology plays a fundamental part in just about every facet of human activity. Its scale, reach and expansion is certainly colossal. For example, OECD countries currently have about one mobile internet subscription per inhabitant. Mobile data usage more than doubled in most OECD countries between 2015 and 2017. By 2021, three connected devices will exist per person around the globe (OECD, 2019[1]).

People now have access to an unprecedented amount of information literally in the palm of their hand. Digital technology – or more accurately, information and communication technology (ICT) – enables us to interact with, manage and share information with others like never before. As a result, most of humankind now inhabits a global '*infosphere',* which has fundamentally altered the way people act and interact (Floridi, 2014[2]). The social and economic impact of this digital transformation (Box 1.1) is rightly compared to previous industrial revolutions (OECD, 2019[1]).

While technologies such as the internet, the smartphone, blockchain and artificial intelligence (AI) may be the instruments of digital transformation, electronic data are its lifeblood. The world now creates more than 2.5 quintillion (2.5×10^{18}) bytes of data every day, meaning that more data have been generated in the last few years than since the dawn of civilisation (IBM, 2017[3]; DOMO, 2017[4]). Almost every human activity now generates data. Modern household appliances are on the internet of things (IoT). This means that people's daily digital footprint will soon begin not only when they check their smartphones, but when they open their 'smart fridge' in the morning.

The fundamental economic characteristic of data (and intangible digital products such as software) is that they have no mass, and can be used and re-used without depletion and at very low marginal cost.[1] Data generated for a certain purpose may be re-deployed in countless ways to answer new questions, build knowledge and generate insights. They are a highly valuable resource and a genuine factor of economic production. Data availability is even used in some countries to attract international investment (Will, 2011[5]; Ministry of Foreign Affairs Denmark, 2016[6]). Data also exhibit many of the qualities of a public good,[2] which makes them particularly interesting to governments and suitable for public policy.

Sectors ranging from, finance, insurance and retail to education, transport and defence have certainly taken advantage of data and digital technology to achieve their objectives, and improve their products and services. The transformation has generated immense value through consumer surpluses and social dividends, as well as profits on the supply side.

The implications for health, a sector where information is critical to success, are profound. Health systems[3] now produce as much as 30% of the world's stored data (Huesch and Mosher, 2017[7]). Collectively, these data contain an immense amount of useful information on health, disease and on how effectively, equitably and efficiently health systems perform. Also, people's daily digital footprint can reveal a lot about their health. Grocery purchases, smartphone app data, web-browsing and social media content all make up an individual's 'digital phenotype'. A recent study used people's web browsing data (the words typed into search engines) to accurately predict the timing and reason for visiting a hospital emergency room (Asch et al., 2019[8]). But the health sector has been remarkably slow to capitalise on these opportunities.

This report explores how health systems can more effectively harness data and digital technology to initiate a positive transformation. This chapter presents its key findings and themes. Section 1.2 examines why health has been so slow to harness the opportunities. The section highlights the key enablers of digital transformation in other sectors that are relevant to health systems, and serves as a precursor to the remaining messages of the chapter and the report. Section 1.3 explores the opportunities presented by data and digital technologies in health. It also summarises how most health systems remain 'data rich but information poor'. Section 1.4 examines the barriers to a digital transformation and outlines the organisational, structural and institutional changes needed to address them. Section 1.5 then makes key recommendations for policy makers to move this agenda forward. The section also estimates the health and economic returns on investing in a digital transformation in health.

Box 1.1. Definitions and the scope of the report

Digital technology refers to electronic tools, systems, devices and resources that generate, store, process and/or transmit data. These range from devices such as smartphones and computers to intangible products such as software, web-based information and communication platforms such as electronic medical records, Artificial Intelligence (AI) and machine-learning algorithms. The internet, for example, itself is a 'general purpose' digital technology, which has had a profound social and economic impact.

In this report, digital technology is used interchangeably with **information technology** (IT) as well as **information communication technology** (ICT). The latter stresses the role of telecommunications in the transmission of data and information and is used frequently in this report.

Data are units of information encoded electronically in binary, machine-readable format used by and produced by digital technologies. **Health data** usually consists of individual, personal health and other related information. These can include a range of data about an individual: history of all medical diagnoses, diseases and medical interventions, medications prescribed, test results, imaging. These may contain information on mental health, genetics, behavioural patterns and social and economic factors. They also include health care administrative data: admissions and discharge data routine operational data, insurance and financial transactional data. Depending on the purpose, health data can identify the individual but can also be anonymised and de-identified.

Digitalisation is the use of digital technologies and data as well as interconnection that results in new activities or in changes or adaptation to existing activities. It is quite distinct to **digital transformation,** which refers to the economic and societal effects of digitalisation as well as its enabling factors such as **adaptation and transformation of organisational structures, processes and behaviour**.

This report is principally concerned with leveraging electronic data to generate knowledge and information for improving policy and practice. Examining digitalisation or specific digital technologies is not the main focus. Data underpin of digital technology, but without digital technology data can not be 'put to work'. The report therefore describes these technologies where relevant. For example, machine-learning algorithms that can interpret medical images, assess the risk of a hospital admission or stratify populations based on health need are examined here. However, these technologies run on data to learn and execute the task(s) they are designed for.

Use of data can be primary or secondary. All data are generated for a specific reason – their primary use. For example, the primary use of insurance claims or administrative hospital data generate information used for management and reimbursement. However, these data can also be deployed (and re-deployed) for secondary clinical, managerial, policy and uses such as examining the safety and efficiency of health care organisations, or the performance of specific therapies and treatments.

Source: European Group on Ethics in Science and New Technologies (EGE), Opinion No 13: Ethical Issues of Health Care in Information Society.

1.2. The health sector is slow to embrace a digital transformation – this requires urgent attention

Many sectors have taken advantage of digital technology. This has led to continual improvement of services and products, and the creation of considerable value on the supply and demand side of the global economy (OECD, 2019[1]). For example:

- Analysis of customer data is used by the airline, banking and retail sectors to improve responsiveness to needs and expectations (OECD, 2017[9]).
- In education and insurance, predictive analytics, machine learning and AI provide information on expected behaviour and activity (OECD, 2017[9]).
- 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[10]).
- By 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 who use these data to inform transportation decision in real-time (OECD, 2019[1]).

Firms, organisations and entire sectors quickly recognised that, unlike other resources, intangible digital goods such as data or software are non-rivalrous and can be shared, used and re-used at very low marginal cost. Data and information are now considered a factor of production – albeit a very unique one – alongside labour, capital and raw materials (Murdoch and Detsky, 2013[11]). For example, routine commercial flights generate a large volume of data on the performance of the aircraft and its component parts, as well as real-time weather information. These data are fed back to the airline. They are also shared with regulators and with manufacturers for analysis aimed at continual improvement along the entire supply chain. Air travel is now one of the safest modes of transport available, and has never been cheaper or more accessible (OECD, 2017[9]).

The health sector provides a stark contrast. Take for instance, the fact that health systems generate mountains of data, but do not routinely re-purpose these for assessing the performance and value of treatments. In some places, it is not possible to detect when patients are re-admitted to hospital if this occurs a different location. More fundamentally, health is one of the few sectors where technological advances result in higher costs and expenditure (OECD, 2017[12]; Marino and Lorenzoni, 2019[13]).

To put it plainly, the sector is a decade or so behind. This represents a considerable amount of foregone health and economic benefits. Despite some signs of progress – discussed below and in the substantive chapters of this report – the consensus is that health systems could and should be doing much more to put data and digital technologies to work.

1.2.1. Digital transformation entails much more than digitising existing processes

A key part a digital transformation relates to how new attitudes and thinking are taken on and adopted. This has been evident in some sectors where disruptive innovators have improved certain aspects of production, which has stimulated adaptation among bigger players. For instance, not too long ago electronic banking was deemed revolutionary. Now the word ‘electronic’ is redundant.

Typically, small-scale disruption is evaluated, adopted and scaled to improve performance across a sector. A related feature, *decoupling*, is another hallmark of a digital transformation. Smaller operators are taking on specific parts of the value chain and improving these from the consumer perspective. There are some signs of decoupling in health. For example, pre-diabetic care, mental health or radiology services are beginning to be outsourced by established actors such as hospital chains, insurers and health systems to

smaller organisations dedicated to more narrow function (Shah, Farkas and Kocher, 2019[14]). *GP at Hand,* a digital service in the United Kingdom providing health advice, triage and remote GP consultations, was launched in 2017 in partnership with a west London primary care practice. The number of patients enrolled with this service rose from 4 700 to over 50 000 within two years. However, the disruption caused by the digital service is challenging the prevailing order and its institutions (Burki, 2019[15]).

Decoupling may seem ill-suited to health. After all, it conflicts with the rhetoric of service integration (which is often implied to suggest vertical integration). However, disruption need not mean fragmentation. It may actually have the opposite effect if innovation is underpinned by a *coherent information infrastructure and policy framework.* The urgent need for these is a key finding of this report.

The health sector has unique characteristics. For example, some health data are very privacy-sensitive. They can also be complex. But this does not fully explain the lack of progress. Other types of data, financial or social security, are also considered sensitive. Data mining techniques to analyse complex, unstructured data are available. Complexity is also not inherent. A hallmark of digital transformation is efficient data exchange. This is made possible with adoption of common standards and protocols. The global internet protocol (IP), which enables the seamless exchange of data across the internet, is perhaps the pre-eminent example of this. Yet harmonisation is still largely lacking in health, making health data more complex than it needs to be.

The lack of a common approach is partly responsible for a health data 'gold rush'. Commercial organisations are profiting from acquiring, harmonising and selling large volumes of personal health data for a variety of commercial purposes (IQVIA, 2019[16]; Forbes, 2018[17]; Fortune, 2016[18]; Computer World, 2019[19]; Healthcare Weekly, 2019[20]). While the commodification of these data is not inherently negative, it does raise a number of questions regarding privacy, consent and efficiency that require a policy response.[4] Regulators and policy makers need to prevent the misuse of personal health data, as well as ensuring that the benefits of their use are distributed equitably. After all, most gold rushes did not end well for the majority of those involved.

Despite the uniqueness of health as a sector, the key lesson from other sectors resonates: that digital transformations are not achieved by simply digitising existing practices. In fact, 45% of companies report that 'digitisation' fails to deliver the expected returns (McKinsey, 2019[21]). Success depends on deeper institutional change. And while the transformation has certainly entailed disturbance to the established order, has made some actors in the global digital economy wealthy, and has had certain negative social consequences, there is little doubt that it has also generated sizable consumer surpluses and welfare (Brynjolfsson, Eggers and Gannamaneni, 2018[22]). In net terms, the principal beneficiaries have been the public.

1.2.2. Lessons from other sectors are relevant in health

Why has health – a sector where information and knowledge are critical to performance and success – been so slow deploy available technology for better information and knowledge?

Inputs are not the reason. The data exist, ready to be exploited. The technologies to extract, manage, transmit and analyse them are also available and are continuously improving. Investment in AI is accelerating worldwide as is the number of registered AI patents (OECD, 2019[1]). The number and proportion of scientific papers using data mining and big data[5] analytics is rising (Galetsi, Katsaliaki and Kumar, 2019[23]). The expertise to put data to work exists – albeit residing mostly in other sectors.

The reasons relate to the very things other sectors have been able to address: the organisational and institutional capacity to harness these inputs. The key enablers – flexibility, re-structuring and working across silos – are anathema to the fundamental way in which health systems are organised. Their institutions, forged in the pre-digital era when it was not possible to combine, share and analyse large amounts of data, are known for being static and resistant to change. In many ways, the arrival of digital technology has simply highlighted these long-standing barriers to achieving health policy objectives.

A digital transformation must begin with an explicit recognition that data are a valuable resource, but have no intrinsic value unless put to work within an enabling institutional environment. This recognition, which in many cases finds expression in strategic orientation (an important element of policy making), must be pan-sectoral in order to begin bridging the silos that impede digital transformation. Digital strategies abound in health, but whole-of-government approaches on which enabling policy frameworks can be built are rare.

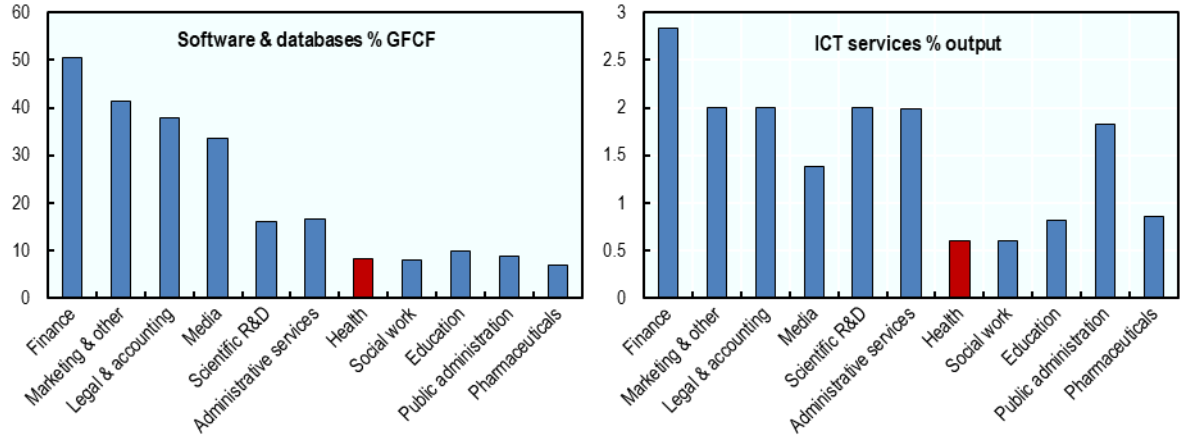
Flexibility is another defining feature of any transformation. This means allowing existing actors and new entrants to disrupt thinking and practice. It also means allowing smaller parts of larger organisations to trial new approaches, which are then evaluated and, if viable, scaled up for broader adoption and until the new practice becomes the new normal across entire sectors – as was the case with e-banking.

Health, of course, is not an area where the *fail early, fail often* mantra holds the same appeal as in Silicon Valley. Nevertheless, a number of examples exist of how innovation is not just possible but can advance health policy objectives. The challenge is to permit some flexibility and controlled disruption, while managing risks. This is eminently possible even in complex, risk laden endeavours. Aviation, for example, has already been mentioned. The British Army has overhauled its operational model, enabling its forces to become more modular and agile (McKinsey, 2019[24]). But in order to work, innovation must be underpinned by common protocols, standards and an integrated information infrastructure. This hinges on appropriate governance designed specifically to maximise the opportunities and minimise the new, unique risks of the digital era.

Capacity to use digital technology, manage data and extract knowledge from them must exist. This requires investment in not just hardware but the expertise to make the most from it. It must target the supply side and the demand side. Providers *and* patients need to be engaged. Surprisingly, OECD countries typically invest only under 5% of health budgets on managing information. In other sectors investment is four times higher (OECD/WHO/World Bank Group, 2018[25]). Closer inspection reveals that the health spends similar amounts to comparable sectors on tangible products such as ICT hardware, computers and network infrastructure (Calvino et al., 2018[26]). However, spending on intangible products such as software and databases, and the purchases of ICT services is comparatively modest (Figure 1.1).

Figure 1.1. Investment in software, databases and ICT services by the health sector

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[26]),:"A taxonomy of digital intensive sectors", https://dx.doi.org/10.1787/f404736a-en.

Lifting productivity and creating value through process innovation

Data-driven technologies are general-purpose, meaning that they can be deployed in almost any aspect of any human endeavour. Their inherent characteristics (low marginal costs, non-rivalrous nature, network effects) provide the means to fundamentally change production functions, thus improving productivity in unforeseen ways (Brynjolfsson, Rock and Syverson, 2019[27]). For instance, not many could have predicted how the internet would transform the global economy. While digital technology has spawned a handful of completely new human activities, its value has overwhelmingly manifested in making routine, existing activities and processes more efficient, more convenient, more productive and cheaper.

Seen in this fashion, a digital transformation has the potential to address *Baumol's cost disease* – the inflationary effects on expenditure experienced in labour-intensive sectors such as health (Baumol, 1967[28]). This need not necessarily be achieved through automation of labour alone. Rather, digital technology, deployed intelligently, can improve just about every facet of production in a health system on both the supply and demand side: service providers become more efficient in producing and delivering services, while consumers become more savvy and competent at using them. As was the case in previous industrial revolutions, this often involves complementing human labour with that of machines.

In health, the potential economic benefits of data- and digitally-driven process innovation are abundantly clear. This is a sector that consumes a tenth of national incomes (a figure that is also rising), where approximately 20% of expenditure does not generate health benefit, and where technological progress tends to *increase* prices and spending (OECD, 2017[29]; OECD, 2017[12]). Investing in a digital transformation is therefore a very attractive proposition (see Section 1.5.4). Rather than creating new things to do, data and digital technology can make existing health system processes and activities more productive and efficient.

The term 'existing processes and activities' may appear to exclude new treatments and therapies – a pivotal aspect of the health sector both in terms of value as well as expenditure growth. However, it includes the *process* of finding innovative new treatments, as well as their regulation, pricing and integration into service provision. All of these activities can be greatly improved by using existing data and digital technology.[6] The combined improvement of these and other processes may be instrumental in tackling Baumol's inflationary effects in the health sector.

But risks and potential pitfalls must be actively managed

It is not suggested the exact processes and behaviours of other sectors should simply be replicated in health. Some, such as excessive hype and overinflated expectations, are best avoided. For example, replacing conventional cars with safe, automated vehicles has been more difficult than expected despite promises by the technology and automotive sectors (The Economist, 2019[30]). The complexity of human-designed systems is often underestimated. The obstacles, however, have been technological as well as ethical and legal. A parallel with the health sector are predictions that health professionals will be replaced by algorithms fed on Big Data. It is best to temper such forecasts with solid analysis.[7]

Perhaps more concerning is evidence – explored in this chapter and in this report – that the benefits of digital technology accrue unevenly across socio-economic and demographic strata. While a digital transformation delivers a net consumer dividend, it can favour the already more well off while others are left behind (OECD, 2019[1]). Given that equity is a key health policy objective, policy makers must actively manage and avoid the perpetuation of disadvantage and inequality.

In the end, a digital transformation in health is not be an end in itself. It is a means to achieving a set of agreed public policy objectives more effectively and efficiently. Data and digital technology can provide the tools but will not achieve much on their own. Caution, prudence and oversight are always advised. Policy makers should take care to avoid the pitfalls and minimise unintended consequences of specific aspects

of digital technology. But the fundamental socio-technical enablers that underpinned transformation in other sectors can and should be deployed to guide a similar transformation in health.

1.3. Despite rising digitalisation, health systems remain 'data rich but information poor'

Using data and digital technologies intelligently harbours a number of opportunities to improve health and health policy outcomes in a number of areas. For example:

- empowering people to take greater control of their health and communicate with their health care team;
- enabling health care providers to have access to consistent and timely information about their patients to promote appropriate and coordinated care;
- Identifying at-risk and complex population groups more accurately, and targeting delivery of appropriate treatments and integrated, people-centred care;
- using existing data ranging from electronic medical records to insurance claims to assess and compare the performance of biomedical technology and treatments;
- extracting information on health system performance to identify waste, inappropriate practice and inefficiency, and improve policy making, system governance and stewardship, including better funding and remuneration;
- harnessing Big Data from within and outside of the health system to improve public health policies and interventions, and prevent the occurrence of disease more effectively as well as enabling effective responses to public health emergencies.

This section briefly describes these opportunities as well as how OECD countries are faring in turning these opportunities into outcomes. It also outlines the critical role of health workforce in a digital transformation. Countries are beginning to recognise and act, but more coherent and proactive policy responses are needed.

1.3.1. The right information to the right people at the right time

The failure to extract and use information contained in health data, which exist already, is a significant missed opportunity to improve services and care. For example, 10% of patients are unnecessarily harmed during care. The health burden of this in OECD countries is on par with diseases such as multiple sclerosis and some cancers. The direct financial impact is as high as 15% of hospital expenditure, and the broader economic drag estimated to be in the trillions of dollars (Slawomirski, Auraaen and Klazinga, 2017[31]). The most common root cause is a failure of communication – information and knowledge not reaching the right person at the right time. Shared electronic information platforms have been shown to improve safety by addressing the communication problem (Banger and Graber, 2015[32]).

Better information exchange makes care not only safer but also more effective and efficient. Care can be better coordinated by different providers and integrated with other services, with better results and less duplication and waste (OECD, 2017[29]). This is especially important for the growing number of people who have multiple chronic conditions, currently estimated to represent at least 20% to 30% of the adult population in OECD countries. For these individuals, accessing care can be frustrating, inefficient and costly in a system fragmented across sectors and disease groupings.

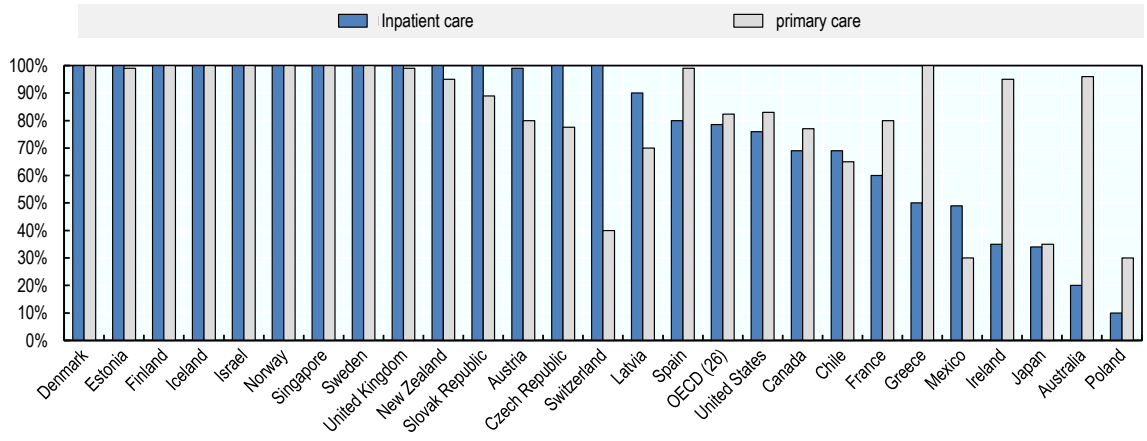
Enabling access to the electronic health or medical record (EHR or EMR)[8] by all actors involved in a patient's care is a key structural component of a high-quality health system (Auraaen, Slawomirski and Klazinga, 2018[33]). While most OECD countries are well on the way to digitalising their health services through the introduction of electronic records in physician practices, hospitals and other settings

(Figure 1.2), only 64% of countries report that these form part of an integrated network where secure but unencumbered exchange of information is possible (Oderkirk, 2017[34]).

This can mean either a 'one patient one record' approach or one made up of disparate platforms that are set up to exchange data and information. A patchwork of electronic records that cannot efficiently link or exchange information with one another is not effective in improving safety or other aspects of care quality such as co-ordination, efficiency and a positive patient experience. From a *systems* viewpoint it is not much better that the pre-digital equivalent of paper records stored in individual health care organisations.

Figure 1.2. Countries are digitalising their health records

Percentage of primary care physician offices and acute care hospitals using electronic medical records, 2016



Note: United Kingdom: England, Scotland and Northern Ireland (excludes Wales).
Source: OECD Survey of Electronic Health Record System Development and Use, 2016; Oderkirk (2017[34]) "Readiness of electronic health record systems to contribute to national health information and research", https://dx.doi.org/10.1787/9e296bf3-en.

Enabling people to access their health records and interact with their own medical information is a driver of high quality people-centred care. Digital technology provides the ideal platform to enable this access easily and efficiently. It is encouraging that approximately 70% of responding countries to the 2016 OECD survey reported that people can access their record. However, only 43% reported that individuals could interact with their own record (e.g. enter information, send requests, communicate with providers). A study by Barbabella et al. (2017[35]) found that the majority of hospitals in Europe (90%) do not permit patients to access their own health data. Elsewhere, access restrictions can sometimes result from legislation. For example, United States federal and state laws allow patients to request amendment to their health record but not to directly interact with their record.

People's rights to access their health records may also be underused. In the United Kingdom, fewer than 8% of patients who were able to access their medical records actually did so (NHS Digital, 2019[36]). In programmes to improve care for multi-morbid patients, tools for sharing of information mainly focus on interactions between professionals and provider organisations, not on making information available to patients (Melchiorre et al., 2018[37]). Access is likely even lower among populations with complex needs. In the Netherlands, for example, just 4% of the chronically ill population reported using a personal health record.

Examples of progress can be found. Estonia has a unified EHR, which enables residents to view all of their medical data in one place – including diagnoses, test results, medications. Residents can also interact with their data. For example, they can update their details, supplement existing information, and carry out

administrative processes such as obtaining a medical certificate for a driver's license without needing a specific appointment. Lithuania (which did not respond to the survey on which Figure 1.2 is based) has implemented a centralised 'one resident – one record' EHR system that covers 95% of the population. It carries all relevant medical information in integrated electronic workflows covering appointments, referrals and e-prescribing. It also enables provider interaction and patients have secure access to their record through a patient portal.[9]

1.3.2. Data can help identify health need and target care more accurately

Analysis of existing health data can enable health service planners and policy makers to identify and target individuals who have complex health needs. These people may not always be in contact with the most appropriate health care providers, making data a valuable resource for creating information on where they reside, their level of need, the type of services they will require and the level of resourcing required.

In Spain, a locally developed risk-stratification tool is used in 14 of the country's 17 autonomous regions. EMR data from primary care providers and hospitals across the regions are linked to create a common data pool. The model uses this pool to identify complex patients based on a classification termed morbidity adjusted groupings (*Grupos de Morbilidad Ajustados* – GMAs). The system supports targeting of care and helps allocate resources according to health need. One limitation is that the GMAs do not capture variables that are not coded in clinical data such as social and economic circumstances, which could be included with linkage of additional data sets.

Many of the Spanish regions have built on this tool to develop integrated care models for complex patients identified. These often use shared electronic care plans to plan and monitor the care patients receive from various providers, relying on a shared EHR to exchange information with a single provider taking on a coordination role. Such models harness shared information systems while alleviating overburdened providers, for instance by reducing unnecessary hospitalisations and the administrative workload of primary care doctors.[10]

The United States Office of the National Coordinator for Health IT (ONC) released Draft 2 of the Trusted Exchange Framework and Common Agreement (TEFCA) in April 2019. This outlines a common set of principles, terms, and conditions to support nationwide exchange of electronic health data across disparate networks. The TEFCA is designed to scale health data exchange nationwide and help ensure that Health Insurance Networks, health care providers, health plans, individuals, and other stakeholders have secure access to their electronic health information when and where it is needed to promote care co-ordination and orientate care around patients' needs.

While some promising examples such as these can be found, there remains a lot more that can be done in this important area of using existing data for the important purpose of identifying and addressing health need.

1.3.3. Most OECD countries are slow to harness data for safer and better treatments

The potential of using data to generate information and knowledge extends beyond improving patient care. Another important area is the assessment and regulation of medical technologies.

Real-world data (RWD) refers to data created during routine health system activity, as opposed to data generated during clinical trials. RWD can be used to generate evidence on how drugs and other medical products perform in routine clinical use. This can complement evidence derived from clinical trials to better inform decisions and actions of clinicians, patients and policy makers.

It also represents value for money. Clinical trials are complex, lengthy and expensive, yet typically include a relatively small number of carefully selected subjects, who may not represent the patients that the product will eventually be used on. Modern analytical techniques drawing on large sets of RWD can include millions

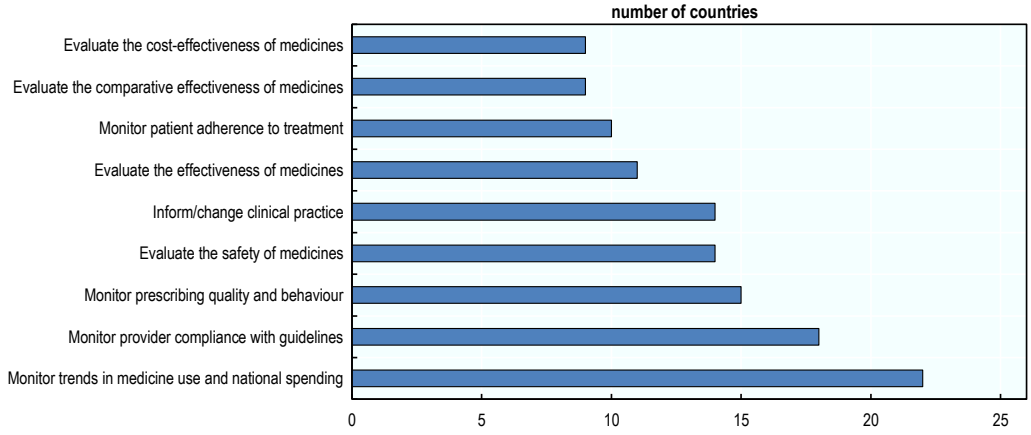
of subjects. The statistical power is comparably large, and advanced methods to limit confounding variables continue to evolve. Real-world trials can now reproduce trial results much faster and at a fraction of the cost (Fralick et al., 2018[38])].

This can deliver faster, safer and better treatments – particularly for emerging health challenges such as dementia and chronic conditions, where pooling relevant data from a range of sources is the only way of devising timely detection and effective therapies.

It can also inform better policy. For example, as evidence of a product's performance accumulates, payers can determine if prices reflect therapeutic benefit – and adjust them accordingly. This can not only improve efficiency and value derived from medical technologies, but also sets incentive signals for future product development.

However, most health systems are not harnessing data to their full potential in this way. The majority of twenty-six OECD and European Union countries surveyed in 2018 on the use of routinely collected data reported that the principal purpose was to monitor medicine consumption and expenditure (22 countries). Eighteen used these data to monitor provider compliance and 15 to monitor quality of prescribing. Meanwhile, 14 countries reported using routine data to evaluate the safety of medicines (Figure 1.3).

Figure 1.3. Routine data are mostly used for monitoring medicine use, expenditure and compliance



Note: In most cases, the routine data described only cover medicines dispensed in the community setting and not medicines dispensed in hospitals.
Source: OECD (2019[39]), "Using routine data to inform pharmaceutical policies", https://www.oecd.org/health/health-systems/Using-Routinely-Collected-Data-to-Inform-Pharmaceutical-Policies-Analytical-Report-2019.pdf.

The positive finding is that at least routine data are beginning to be used. However, in most cases the data excluded drugs dispensed in hospitals, which represents a considerable proportion of medicine consumption. This suggests problems with data linkage and information infrastructure. Moreover, only nine countries reported that evidence generated from routine data was considered by health technology assessment agencies (HTA) in their decision-making (OECD, 2019[39]).

Overall, the majority (19) of responding countries answered 'no' to the question of whether routine data were used to their full potential. The main barriers cited were prohibitive privacy legislation and poor data quality (governance issues) and lack of capacity in terms of infrastructure as well as analytical expertise (OECD, 2019[39]).

Perhaps the best example of systematic use of routine data at a national level is the United States Food and Drug Administration's (FDA) 'Sentinel' Initiative. The Sentinel programme monitors the safety of medical products in routine use by accessing personal health data – scattered across a large number of

health care organisations, payers, dispensers and other agencies – of over 200 million people. To ensure security and privacy, data never leave their location. Instead, single electronic queries are sent across the entire network. This feature is enabled by common data standards and protocols. Identifying safety problems the old way used to take years. Sentinel does this in weeks or months, reducing harm while saving money and time. Since its establishment in 2014, the initiative has enabled important regulatory decisions. It is also eliminating the need for many expensive post-marketing studies, which can cost millions of dollars to run.[11]

1.3.4. Big data are not used to their full potential in public health

Public health is arguably *the* area where data – especially 'big data' flowing from non-traditional sources outside of the health system such as social media, web searches and environmental data – can be put to work to advance health and prevent disease. These data can complement traditional information sources to answer many questions and steer public health policy in three key ways:

1. Allowing a more precise identification of at-risk population groups ('precision public health');
2. Enabling better surveillance of both communicable and non-communicable diseases;
3. Facilitating better targeted strategies and interventions to improve health promotion and disease prevention.[12]

These new methods can be used to tackle a range of public health priorities, such as monitoring and responding to food-borne outbreaks, identifying behavioural risk patterns across populations, or monitoring signs of mental ill-health such as suicidal ideation.

Much promising activity is already happening at the municipal level. "Smart Cities" demonstrate how integrating transportation, mobility, food safety and environmental data can contribute to more effective and efficient health promotion and disease prevention. For example, the city of Chicago used publicly available data from a variety of sources (ZIP codes, business licenses, building code violations, and a phone hotline for complaints) to predict restaurants most likely to be in violation of health codes. More recently, researchers used anonymised Google search terms and geolocation data of individual users to identify food-borne disease outbreaks across the city. Problems were identified considerably faster and more accurately than with traditional surveillance methods.

At the national level, Korea is in the process of integrating the national health insurance database (NHID) with clinical records, health care activities as well as data from outside of the health system including climate, pollution and geolocation data. To date, analytical uses of the NHID have included, for example, identifying causality and predicting risk by linking health-screening data with medical history and socioeconomic status, and a surveillance system to target chronic diseases, based on information of individuals' use of health services. The amalgamation will further equip decision makers, public health experts and citizens with more detailed information to pursue a range of efforts to improve public health and prevent disease.

Some countries have also started exploring the possibility of using genetic data to inform public health prevention. In Estonia, two large-scale clinical trials are working to better target preventive health care services at patients at higher risk of cardiovascular disease or breast cancer, based on genomic algorithms using data from the Estonian Genomic Center. In the United States, a USD 215 million Precision Medicine Initiative was launched in 2016. This will include, among other projects, the *All of Us* research programme, a 1-million participant study whose mission is "to accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care" by studying "individual differences in lifestyle, environment, and biology".

Big data present a number of opportunities but also have some inherent limitations as well as challenges relating to *inter alia* ensuring their quality and managing their security and privacy implications. For

example, the temptation to over-rely on big data without robust methods for interpreting it can lead to *apophenia*: "seeing patterns where none actually exist, simply because enormous quantities of data can offer connections that radiate in all directions" (Boyd and Crawford, 2012[40]). Approaches using big data should therefore *complement* – not replace – traditional public health surveillance methods. Nevertheless, big data have the potential to facilitate the more effective translation of knowledge into effective public health policy, by enabling a better understanding of the interaction between behaviour, genetics, and the physical and social environment.

Transparency represents a key element that can facilitate the success of public health initiatives based on big data. Sharing data and algorithms with other stakeholders (e.g. collaborations between academia, public health departments, industry, and citizens) enables a more effective use of data and facilitates the early detection of any problems, as well as allows other public health authorities to implement similar successful interventions. But transparency needs to be underpinned by good data governance, which ensures that security and privacy are maintained and maximises the utility and use of available data to generate valuable knowledge.

1.3.5. Harnessing data to improve efficiency and value across the health system is rare

Using available data can drive considerable improvements in how complex health systems are managed. The knowledge extracted from data can help decision makers identify and act on problems such as waste and inefficiency, and to make the decisions, and judgements needed for a health system to function. This includes setting priorities, and allocating resources across populations and competing programs.

In some health systems the proportion of unnecessary treatments, procedures and therapies exceeds 40% (O'Neill and Scheinker, 2018[41]). Identifying wasteful spending through better use of available data is a prime opportunity for improving efficiency and outcomes (OECD, 2017[29]).

For example, the Washington State Health Care Authority (WA HCA) has linked claims, billing and EHR data of 2.4 million insured individuals to examine inappropriate and wasteful practices. The algorithm classifies services as necessary, likely to be wasteful, or wasteful. The benefit of linkage across the three data sources is that it allows more nuanced analysis, incorporating the individual context of each case, as opposed to simply tallying the number of procedures on a 'low value' list.

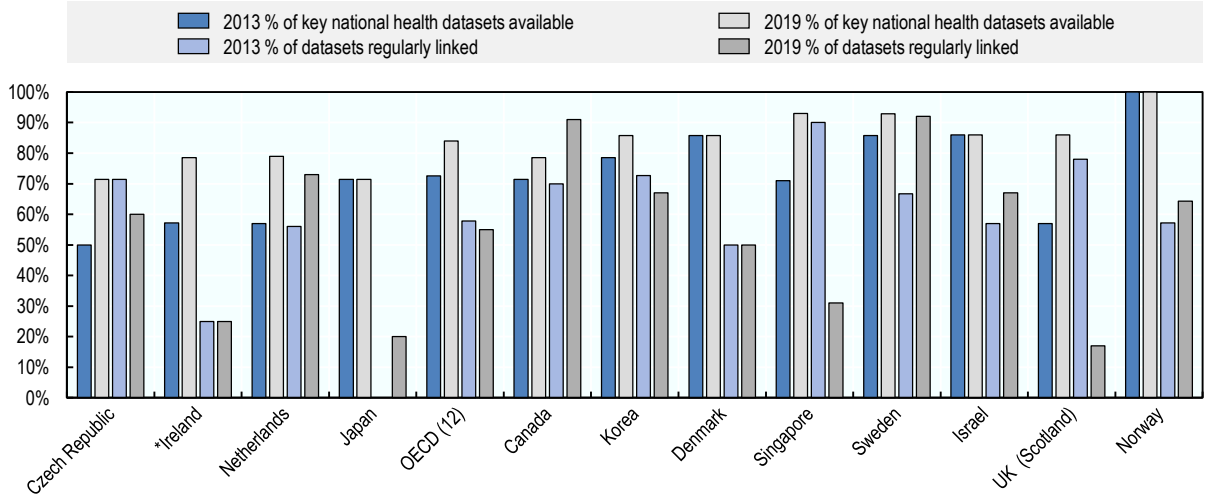
Of the 1.52 million services analysed 44% were classified as wasteful (i.e. not adding any health benefit for the recipient). Spending on these services amounted to USD 282 million, or 36% of WA HCA expenditure (WHA, 2018[42]). A similar study in Saint Louis, using data of 1.6 million individuals, identified 46% of services as unnecessary (National Alliance Of Healthcare Purchaser Coalitions, 2018[43]).

Clearly some people receive unnecessary treatments while others, in greater need, miss out. In addition, unnecessary duplication and wasteful administrative processes abound in all health systems. The challenge is using this information and knowledge to develop effective policy responses to reduce these inefficiencies and redeploy resources where they are most needed.

Data linkage, by shedding light on what is really going in a complex health system, is a critical step to assess performance, identify problems such as unwarranted variation, and enable smarter resource allocation. However, a survey of OECD countries conducted in 2013 and repeated in 2019 found considerable variation in both the availability and readiness of key data sets, and their regular linkage for secondary purposes such as system management (Figure 1.4). While the 2019 information is preliminary and the participation of a greater number of countries in the 2019 data collection is necessary for understanding change over time, the results suggest that key health datasets may be less likely to be regularly linked than they were in 2013.

Figure 1.4. Availability of data is growing but their linkage appears to be stagnant

Percentage of key data sets available and regularly linked, 2013 and 2019



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).
Sources: OECD (2019[44]) "Survey on health data governance: preliminary results"; OECD (2015[45]) "Health Data Governance: Privacy, Monitoring and Research", https://dx.doi.org/10.1787/9789264244566-en.

One possible reason for the reported reduction in linkage is that the European General Data Protection Regulation (GDPR) came into force in 2018. The GDPR affords personal health the highest level of protection, and has brought security into sharper focus within the European Union and beyond, with many countries still adapting their systems to respond to the new regulation. Protecting data and putting them to work are not mutually exclusive – both can be achieved with strong data governance frameworks.

Nevertheless, linking disparate datasets to create new knowledge for policy and other purposes is eminently possible. In New Zealand, personal health and other public sector data are linked to create 'virtual registries' for diseases such as diabetes (Jo and Drury, 2015[46]). These registries track the health care activity and outcomes of the relevant patient population enabling better assessment, decision-making and resource allocation. Traditionally, such registries are constructed in parallel to existing data sources. This can cost millions of dollars to establish and maintain. Harvesting the data from existing data sets is much cheaper and more efficient. Similar linkage in New Zealand also enabled detailed cost-of-illness study of multi-morbidity, generating hitherto unknown knowledge on the expenditure profiles of patients with various combinations of chronic diseases (Blakely et al., 2019[47]).

Detecting fraud, a significant burden on many health systems (OECD, 2017[29]), can be enhanced with modern data analytics. The United States Department of Health and Human Services-Office of Inspector General (HHS-OIG) mines available data and applies predictive analytics and modelling to enhance oversight of the Medicare and Medicaid programs for fraud. Multi-disciplinary teams use near real time data to examine claims for known fraud patterns, identify suspected fraud trends, and to calculate ratios of allowed services as compared with national averages, as well as other assessments.[13]

1.3.6. Information systems can enable better health funding models

A major contributor to the problems faced by health systems is the way services are paid for. The rise of chronic diseases and longer life spans means that service delivery should be approached in a more longitudinal and coordinated way that crosses boundaries between sectors (including social care) and

settings. Remunerating individual service parcels is becoming less and less conducive to ensuring effectiveness and efficiency in the majority of health care activities.

Payment systems that encourage integration and that cover entire care pathways, better outcomes and efficiency have been discussed for some time. Alternative models to meet the challenges of rising patient complexity and achieve policy objectives include: additional payments made before during or after service delivery for specified outputs or outcomes; bundling – a combined, single payment for entire care cycles across settings and including primary and tertiary care, imaging and pathology, rehabilitation and follow-up care; and population-based payment, in which groups of health providers receive payments on the basis of the population covered, in order to provide most appropriate health care services for that population (OECD, 2016[48]).

While these non-traditional payment models vary in their design, incentives and structure, they have one thing in common: their success relies heavily on an information system with the capacity to integrate data on inputs, outputs, processes and outcomes. This was difficult in the analogue era – part of the reason that fragmented payments such as fee-for-service became the dominant model. However, electronic linkage of clinical, administrative, financial and other data makes these new approaches possible. Payments can be bundled across a set of providers and activities, with data systems ensuring that each component is remunerated appropriately. The clinical and budgetary consequences of a medical error 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. This encourages better coordination and communication (the lack of which is the most common cause of adverse events). Good information systems can ensure that payment for achieving agreed performance metrics is based on reliable data from several sources that can be more accurately adjusted for patient complexity and other confounders. Technologies such as blockchain, which can enable deployment of 'smart contracts', can further enhance the reliability of these payment models.

Similarly, population-based remuneration can also be adjusted to reflect health need, making it possible to transform care. The possibilities for these innovative approaches to payment expand when health data can be linked with social care data. Enabling payment models that encompass a broader range of health determinants could yield better health outcomes than the current fragmented approach. Integrating data in this way increases the accountability of each provider who contributes to a patient's care pathway.

While the possibilities are many, examples are few, especially at the national level. Partners HealthCare in the United States has implemented a bundled payment framework that encompasses acute and post-acute care providers. The framework comprises four parts: risk stratification of patients, care team convening and planning, monitoring and communication, and patient engagement. The cornerstone of this model is an integrated EMR that enables communication between providers and patients, and that supplies the data for risk stratification and eventually payment. But implementation was heavily reliant on organisational leadership and policy (Safavi, Bates and Chaguturu, 2019[49]).

Some countries are laying the foundations for new payment and resourcing mechanisms. Finland, for example, is establishing a one-stop shop for all secondary use of health and social care data, enabling a wider set of information to be integrated for use by the health system. 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 resources across the country's regions.[14]

However, data infrastructure and digital technology merely provides the possibility for changing the way providers are paid. Institutional and policy changes are needed to adapt remuneration towards a model more suited to modern demands (See Section 1.4.5).

1.3.7. Preparing the health workforce to make the most from a digital transformation is a challenge

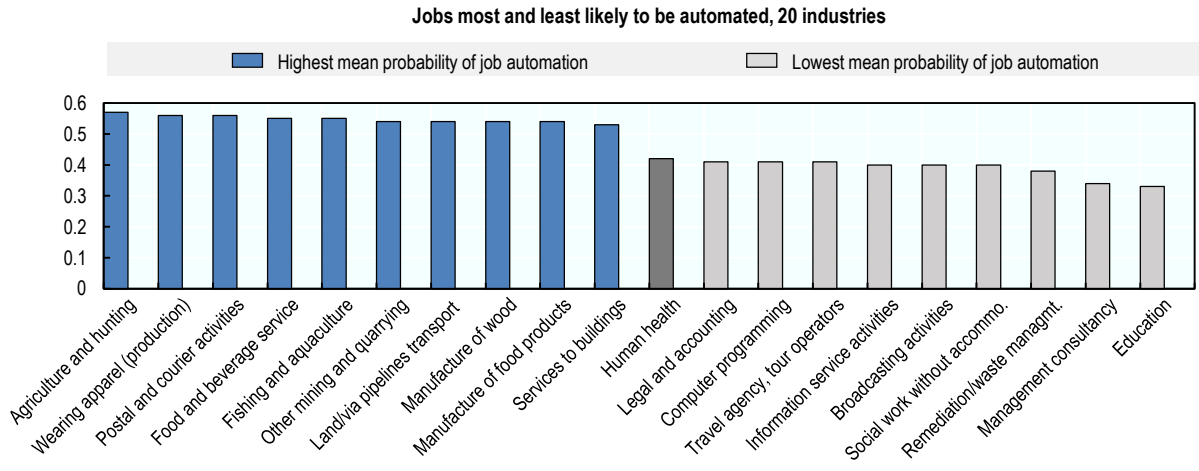
The health workforce is pivotal in a successful digital transformation. OECD analysis suggest that automation will create significant workforce disruption in modern economies. But the perception that health workers will be replaced by machines is not supported by the evidence, with their roles and tasks among the least likely to be affected (Figure 1.5). Nevertheless, majority of health workers are likely to see changes in their task composition towards tasks that are difficult to automate, such as those related to creative and social intelligence, teamwork and other 'soft' skills.

As discussed, digital technology offers opportunities to improve care delivery. Data-driven tools can support health workers in performing tasks that are repetitive, time-consuming, and heavy on data processing, such as selecting irregular results from large volumes of preventive or routine chronic care tests, synthesising information relevant for a given patient's condition from numerous sources (patient records, archives, guidelines, specialist recommendations), or analysing patterns in patient outcomes for regular improvements in practice.

Machines are also beginning to match human performance and accuracy in, for example, analysing radiological images and retinal scans. Workers aided by these tools could become more productive. This includes having greater opportunities for face time with patients or colleagues, and to employ human skills to address their professional obligations more effectively and with requisite empathy.

Figure 1.5. Health sector jobs are at a comparatively low risk of automation

10 sectors with the highest, and 10 with the lowest risk of automation for average job within the sector



Notes: High mean probability of job automation means that the mean job in a given sector is highly automatable based on tasks it involves. Low mean probability of job automation indicates that the mean job in a given sector might change with regards to how some of its tasks are carried out. Not all tasks related to caring for and assisting patients that cannot be automated could be included in the calculation; hence, estimates for the health sector are biased upwards.
Source: Nedelkoska and Quintini (2018[50]), "Automation, skills use and training", https://doi.org/10.1787/2e2f4eea-en.

Leveraging data to improve clinical as well as other activities of health care systems also means that new occupations – and roles within existing occupations – are likely to emerge. For example, oncologists, radiologists and anaesthesiologists could work with coders and data scientists to design, evaluate and refine the algorithms that enhance their practice.

However, things are not as simple as feeding reams of data into a machine – as the aforementioned problems with of autonomous vehicles suggest (Section 1.2.1). In the health space, difficulties with initiatives such as IBM 'Watson' suggest that the automation of complex and nuanced clinical decision-making is more complex than initially thought. Watson was trained to give treatment advice for cancer patients, but frequently made unsafe recommendations. A key problem was that Watson was trained on hypothetical, not real-world data, highlighting the importance of strong data governance to enable putting real-world data to work for productive purposes.

Nevertheless, the fact remains that health workforces are ill-prepared for a digital transformation, which makes change harder and slower. For example:

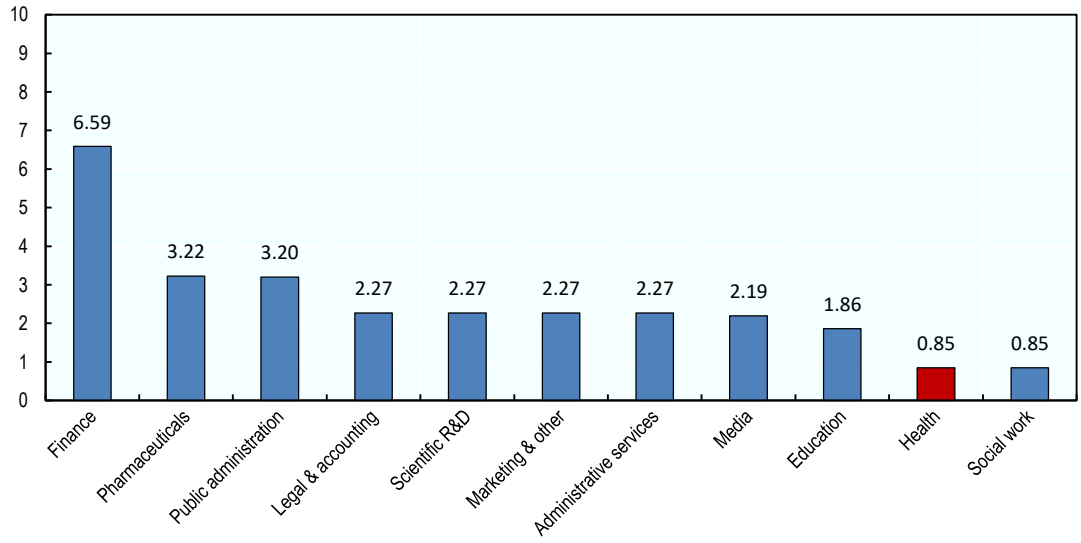
- Requirements to undertake continuous professional development have not kept up with technological and labour markets changes affecting the economy as a whole. Up to 70% of health professionals report not being accustomed to using digital solutions due to gaps in knowledge and skills in data analytics (Hegney et al., 2007[51]; Foster and Bryce, 2009[52]; Skills for Health, 2012[53]; European Commission, 2013[54]; European Health Parliament, 2016[55]; Quaglio et al., 2016[56]; Melchiorre et al., 2018[37]). A health professional who does not understand how an algorithm behind a clinical decision support tool was developed, or the data used for its conclusion, will see it as a "black box" and may be reluctant to use it (Galetsi, Katsaliaki and Kumar, 2019[23]).
- A fragmented, disease-centred approach to health care delivery means that many digital solutions are not fully deployed because of limited teamwork among health workers belonging to different professional categories, specialties, or provider organisations (Rudin et al., 2016[57]).
- Tasks in health care are defined based on the type of employment. For example, only doctors can perform certain tasks. This limits the opportunity to leverage digitalisation to improve efficiency and address shortages by facilitating shifting of tasks from doctors to nurses and community health workers.
- In-house expertise to put data to work is also missing. Making the most of digital opportunities and ensuring that the changes result in favourable outcomes requires ICT specialists and data scientists. Sector-specific specialisation for these occupations is becoming increasingly common and valued. Yet, recent OECD analysis suggests that the health sector has relatively few specialists (less than 1% of employees) in these fields compared to education, public administration and finance (Figure 1.6).

Some health systems are addressing these issues, particularly in terms of improving digital literacy among their health workers. Australia, Canada, Norway, Switzerland, New Zealand, and the United Kingdom completed a review or established a regular process to assess how technological and other developments (including ICT, AI, genomics, or demographics) are likely to change the skill requirements and the roles and functions of health workers over the next two decades. These reviews include the consequences for the education of future, and the training of current health workers.

Based on such a review, the Norwegian government, for example, is currently restructuring national curriculum regulations in health to make these more future-oriented. In Switzerland, eHealth Swiss has published guidelines for educators on how to integrate digital-health topics into the education and professional training of health workers. Canada Health Infoway – an independent, not-for-profit organisation, fully funded by the federal government – supports the Digital Health FACTS programme, which engages inter-professional faculty and students of medicine, nursing, and pharmacy to promote and scale up development of digital skills that match the demands posed by the emerging digital technologies.

Figure 1.6. The health sector has a relatively low proportion of ICT specialists

ICT specialists as a % of total employment, by sector (2013-15)



Note: Calculated as the number of workers employed in ICT specialist occupations, over total employment in the sector. Sector-specific values are weighted averages over the considered countries, where weights are equivalent to the country's total employment in the sector. The values are then averages 2013-15. Countries covered are: Australia, Austria, Denmark, Finland, France, Italy, Japan, the Netherlands, Norway, Sweden, the United Kingdom, and the United States.
Source: Calvino et al. (2018[26]), "A taxonomy of digital intensive sectors", https://dx.doi.org/10.1787/f404736a-en.

Many countries have developed new programmes and accreditation standards in Clinical Informatics, with some – the United Kingdom and the United States, for example – creating hybrid degrees that closely tie clinical leadership with informatics and digital transformation. These hybrid programmes allow clinical leaders to obtain new competencies in ICT-based quality improvement and change management to provide the needed leadership and ensure buy-in from health workers in general. In the United States, the HITECH Act funded two distinct health IT workforce training programs, which have trained 21 437 students and working professionals.[15]

However, more is required to ensure that the skills health workers (and the health workforce) needed for effective and safe use of emerging digital tools, technologies and data analytics are taught routinely. The same goes for human capital in administration, management and policy making, where digital, data and statistical literacy are equally crucial to drive positive transformation. With the current accelerated pace of technological development, it will become more necessary for health workers to regularly update their skills. As such, it is important to reconsider the skills delivery pathway, and encourage a shift towards a lifelong learning model. But concrete strategies for achieving this are still to be formulated in most countries.

1.4. Tackling the barriers to a digital transformation needs an overhaul of policies and institutions

Failing to implement and harness a digital transformation is a missed opportunity for better care, more effective treatments and improved health system performance. The lack of progress pints to significant barriers. But these are not technological. The data and technology are, in the main, sufficient. The barriers

are structural, organisational and institutional. They have been in place since long before digital technology made it possible to generate, transmit and analyse large amounts of data easily. They include fragmentation and silo thinking – a renowned, persistent and frustrating characteristic of health systems.

These barriers are habituated and firmly baked into how health systems function. They are difficult to change without a fundamental overhaul. Addressing them requires changes and adaptation on a number of fronts. The most critical are outlined in this section. They include changing professional attitudes and skills, updating ethical frameworks, engaging health system users, opening data availability and facilitating their integration, and an environment that creates incentives and behaviour for a transformation to take hold.

1.4.1. Transforming skills and attitudes across the sector

Using data (and to a lesser extent digital technology) is still too often seen through a lens of risk as opposed to opportunity. This is an outdated, 20th century view, but is reflected in existing policies that make it very difficult to put data to work. Too often use of data is seen principally as a risk to privacy, cybersecurity threats and the costs of security breaches (including liability).

While data security and privacy are crucial, forward-thinking countries and health systems equally recognise and communicate the opportunities of using data. In contrast to previous decades, the 21st century approach is to maximise the benefits while minimising the risks. Both are possible but only with strong, fit-for-purpose governance and policy frameworks.

Paternalistic attitudes that tend to prevail in health sector are also not conducive to promoting the use of data and information for purposes ranging from empowering people to take greater control of their health or effective sharing of data across specialties and settings of care. Beyond care delivery, this presents a barrier to secondary uses of data for research, public health and performance monitoring.

The way in which digital tools are developed serves to illustrate why this is a problem. For example, few health apps are designed with involvement of the end user – the individual with a particular health need or the health professional. Often, there is little input from clinical experts. More typically, digital tools and gadgets are developed by IT experts. Another example are EHRs, which are often developed and designed with a purpose other than making clinical care more effective and efficient. The technology ends up 'getting in the way' of not only delivering good services but also of generating high quality data that can then be used for other important purposes.

A fundamental part of addressing this revolves around equipping the entire health workforce with the skills and attitudes to make the most of data-driven technologies. For example by reforming both initial training and continued professional education and supporting health workers in acquiring new digital and teamwork skills. It concerns how health workers are socialised and taught to interact with colleagues in their as well as other professions and their patients. It also requires ensuring that individuals and patients feel empowered to work in partnership with their care providers (see Section 1.4.3).

As discussed, most countries are still at the preparatory stage of restructuring of health workers' curricula to respond to the demand for updating of skills. Similarly, courses and teaching methods such as inter-professional education that aim at reinforcing skills related to teamwork and inter-professional collaboration are not yet routinely included in the core curricula. Only some countries – Canada, for example – have built in these skills explicitly into their core competency frameworks informing health professional education. The need for strengthening the skills of health workers to work with (as opposed to around) patients, such as skills in effective person-centred communication and shared decision-making, is also usually marginalised in education and training (OECD, 2018[58]).

Other opportunities include facilitating the integration of new professions and roles in health systems and relaxing rules around the division of work between health professionals, in light of the reorganisation of

tasks that digitalisation can offer at all levels of the health system. More than half of the OECD countries have made progress in this direction by expanding the roles of nurses and allowing task shifting from physicians (and nurse practitioners) to nurses (and nurse assistants) (Maier, Aiken and Busse, 2017[59]) and by creating new medical specialists such as Clinical Information Officers.

1.4.2. New ethical frameworks are needed

At the new digital frontier, a growing number of health care activities will be performed by humans together with machines. How do health workers answer questions about collaborating with AI? Even relatively simple machine-learning models already used – such as those automatically stratifying patients into at-risk and intervention groups – give rise to questions regarding health workers' and machines' respective roles, accountability, and about how to ensure that digital systems do not crowd out the personal touch between patients and providers.

Other questions concern how to inform a patient when a risk-prediction model did not recommend treatment, what mechanism exists to override the model's recommendation if necessary or, again, what happens if the model's recommendation leads to a suboptimal outcome.

No progress will be made unless professional and ethical frameworks are updated. The 2019 OECD Recommendation on Artificial Intelligence can guide countries in this regard. The recommendation comprises two sections. The first outlines the principles for responsible stewardship of AI (inclusivity, sustainability, human-centric values, transparency, security, safety and accountability). The second lays out the policy requirements for trustworthy AI (investment, a digital ecosystem, an enabling policy environment, building human capital and preparing for labour market transformation, and international co-operation) (OECD, 2019[60]). Further delay will make health professionals hesitant to use data-enabled tools and other technologies that enhance cooperation among providers across settings.

The novelty and complexity of big data analytics raises a new set of ethics-related challenges for researchers, regulators and policy makers (Ienca et al., 2018[61]). Growing possibility to use non-traditional data sources such as social media are also challenging the existing ethical frameworks, especially when these data are used for purposes that benefit public health, such as disease surveillance and outbreak management. Work is needed by researchers, ethicists and policy makers to develop acceptable decision making frameworks. For example, Vayena et al. (2015[62]) established three categories for the ethical use of personal data in public health: 1. Context sensitivity (e.g. commercial versus public health use); 2. The nexus of ethics and methods (e.g. robustness of algorithms and data provenance); and 3. Legitimacy requirements (e.g. pest practice, regulatory bodies, public communication).

Data ownership is another related area requiring ongoing discussion (Koskinen and Kimppa, 2016[63]). Here, two challenges are emerging. First, the commodification of health data, with commercial entities acquiring and on-selling personal data for commercial purposes. While these data are typically, but not always, de-identified this still raises questions about consent, ownership and about who should profit from the knowledge extracted from them. Evidence suggests that the public are reticent about their data being used for commercial purposes. Yet a considerable part of health system activity could be deemed commercial and certainly has a commercial component. Excluding companies with the expertise and resources from using health data to, for example, develop improved diagnostic tools or precision therapies that maximise clinical effectiveness and minimise risk, may inhibit potential advances to human health and welfare.

Second is the opinion that individuals are the sole 'owners' of their data. In a world where these data could theoretically be re-deployed in an infinite number of ways, this becomes an important issue and a technical as well as policy challenge. Ownership can be debated based on who paid for the activities that generate the data (Koskinen, Kainu and Kimppa, 2016[64]). If paid for by a third party (typically the taxpayer or insurance plan enrolees) data may be considered a public good with the payers as well as the data subjects

potentially entitled to a say in how the data are used (Rodwin, 2009[65]). These and other questions become even more challenging when genomic data are considered.

Even where personal health data are voluntarily sold by the data subject, this emerging market needs to be examined through the lens of ethics and policy. People should have the opportunity to sell their data. But the likelihood that these people would overwhelmingly be from the poorer and more vulnerable social strata, and the consequent risk of exploitation needs to be considered. For similar reasons, the World Health Organisation advises against paid organ donation (World Health Assembly, 2004[66]). In addition, the potential bias in the data could affect the findings of research and other outputs they are used for.

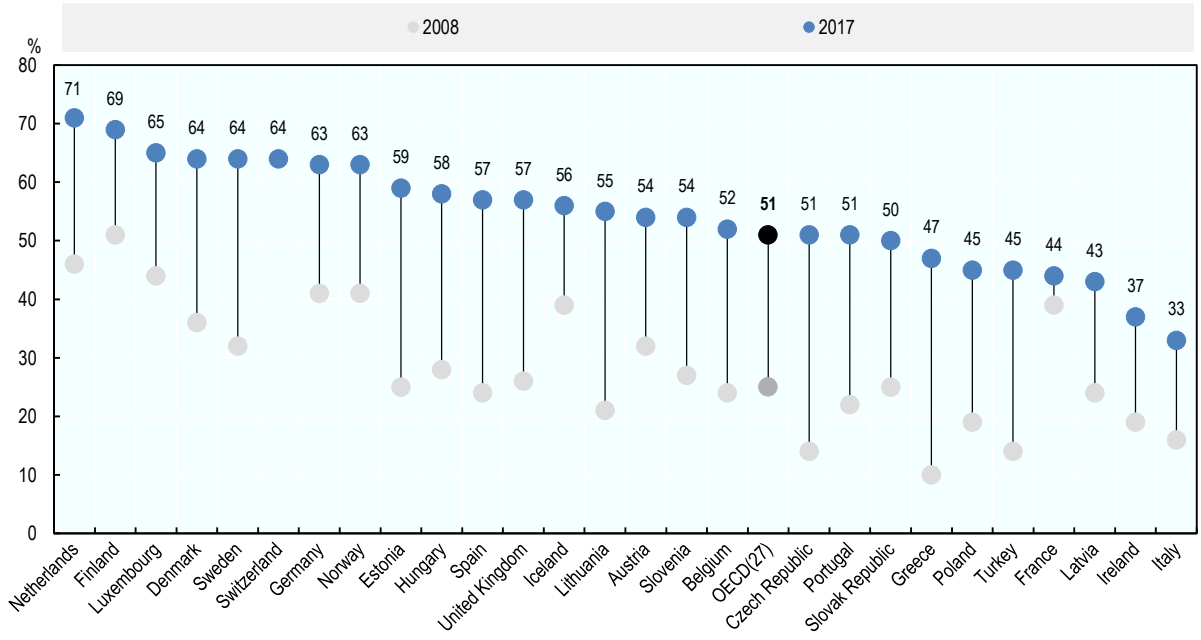
Clues on where societies stand on these issues can be found in regulatory frameworks such as the GDPR, which recognises the societal benefits that can be derived from health data (and puts these data in a special category). But this is a fast-moving field and these questions require deeper, ongoing discussion and the development of dedicated, clearly articulated ethical frameworks and charters.

1.4.3. Engaging patients while ensuring that no one is left behind

People appear to be quite willing to engage with data and information. In 2017, 3.7 billion health related smartphone apps were downloaded globally, up from 1.7 billion in 2013. The proportion of adults seeking health information on line more than doubled between 2008 and 2017 (Figure 1.7).

Figure 1.7. More people are seeking health information on line

Percentage of adults who sought health-related information online, 2008 and 2017



Source: OECD (2019[67]), "ICT Access and Usage by Households and Individuals", https://dx.doi.org/10.1787/b9823565-en.

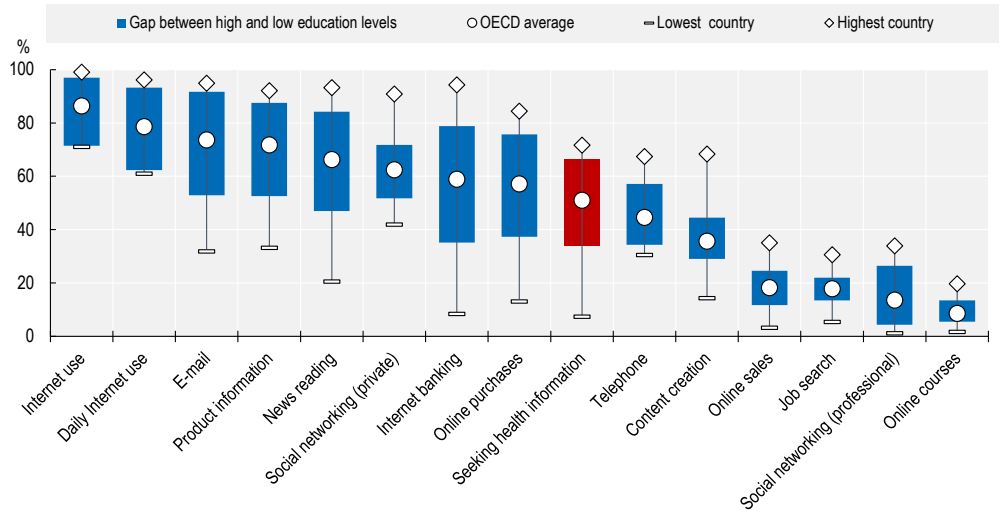
Digital transformation holds some promise to 'democratise' health and health care, and certainly to helping people better manager their own health. But for this to happen in practice, without widening health disparities, more needs to be done. For example:

- *Helping patients access and use effectively their own medical records*. Section 1.3.1 outlined the growing digitalisation of health records and the rising proportion of countries that enable people to access their data electronically. However, few appear to permit individuals to interact with their own data and evidence suggests that a small proportion of people actually do so (especially those with high levels of health need – see below). In some cases legal restrictions are in place preventing interaction with data. These may need to be re-examined with a view to what is best for health outcomes and care quality.
- *Improving health and digital literacy is key*. In 18 OECD countries recently surveyed, at least 30% of the population has poor health literacy levels and in 12 of those countries the proportion is over 50% (Moreira, 2018[68]). Ways to address this gap include raising digital and health literacy, but also better design of web portals or smartphone apps as well as better information about their availability.

  Canada Health Infoway recently launched a country-wide campaign, *Access 2022*, to promote the use of electronic health records by patients and health professionals. In Norway, the government has allocated NOK 27.5 million since 2014 to increase participation in the digital health portal and developed training programs for digital skills at the municipal level.
- *Focussing on uptake among the patients who stand to benefit the mos*t. Evidence suggests that the very complex or vulnerable people that could benefit the most from better care models do not engage with digital technology like their more healthy counterparts. The structural inequalities of digitalisation, which mirror more long-standing social stratification (Figure 1.8), are very telling in this context. In the Netherlands, for example, just 4% of the chronically ill population reported using a personal health record. Addressing this requires a specific focus on vulnerable population segments. For example, educational courses and tutorials targeted at patients with low digital literacy have been implemented in Estonia and are being trialled in the United States.

Figure 1.8. Socio-economic disparity is observed in most on line activities – including seeking health information

Diffusion of selected online activities among individuals aged 16-74 in OECD countries, 2018



Source: OECD (2019[67]), "ICT Access and Usage by Households and Individuals", https://dx.doi.org/10.1787/b9823565-en.

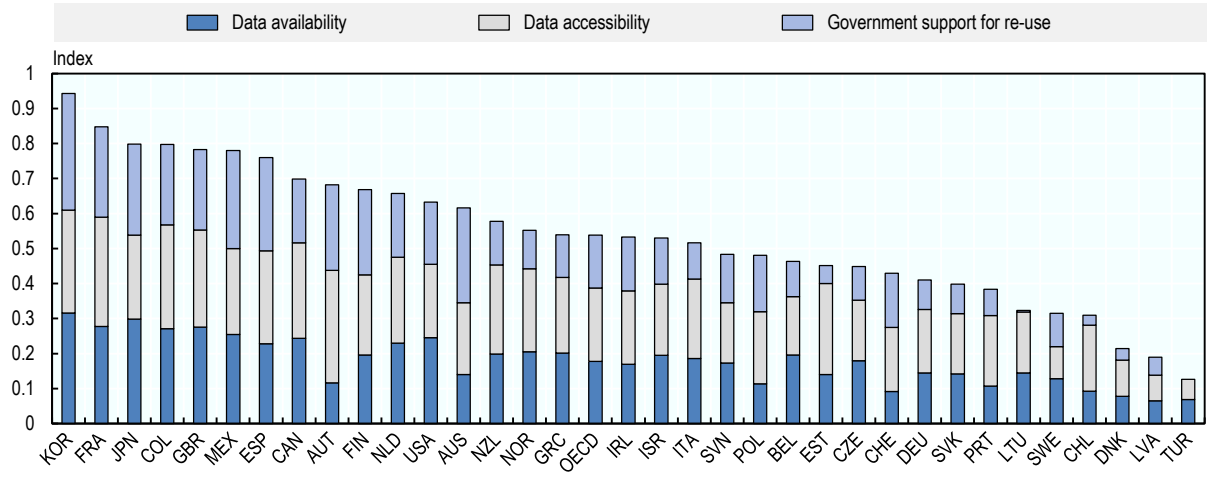
1.4.4. Opening data availability and facilitating their integration

The institutions and habits formed in the pre-digital era have entrenched fragmentation and a silo approach to doing things. Meanwhile, the utility of data for producing actionable knowledge rises exponentially if they can be combined and pooled – a requirement that is blocked by fragmentation.

Making data available to all stakeholders who can turn them into valuable knowledge is also important. In non-health sectors, opening public sector data has been shown to catalyse innovation by the private sector (OECD, 2019[1]). The openness of government data in general varies across OECD countries (Figure 1.9). Opening access to non-rivalrous health data will help transition them towards being seen as a public good. The benefits to societies and humanity of making them available on the broadest possible scale can therefore be maximised (Grossmann et al., 2010[69]; OECD, 2019[1]).

Figure 1.9. 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[1]) "Going Digital: Shaping Policies, Improving Lives", https://dx.doi.org/10.1787/9789264312012-en.

Addressing the issue of openness, and facilitating comprehensive data linkage require policy to create the right environment and implement the right levers to make progress. For example:

- *Improving the preparedness for EHR data to be used for secondary purposes such as research*. Most countries are capturing clinical data electronically, but based on a 2016 OECD survey, only the countries in the upper right quadrant of Figure 1.10 report readiness to put them to work. Of note is Estonia, which has implemented a state-of-the-art digital infrastructure. Yet, it reports not being very well prepared to use this information for secondary purposes, highlighting the need for data governance and capacity to put data to work. The required operational, policy and governance levers include:
    - A national plan or strategy that includes the secondary uses of these data.
    - Having a legal framework that enables these data to be securely extracted and used for secondary purposes
    - Building the capacity to analyse the data to generate meaningful information and knowledge
    - Ensuring data completeness (population coverage), minimum data specifications, common data terminology standards, and unique patient and provider identifiers.

- Financial incentives to not only adopt and maintain high quality electronic records, but deploy data and digital technology to improve services and outcomes (see Section 1.4.5).

- *Encouraging common approaches to data terminology and exchange standards.* The lack of standards creates barriers to – and inefficiencies in – sharing and diffusing data within countries and across them. Other sectors have developed protocols and standards for computer communications, data exchange and cybersecurity – to the benefit of entire economies and societies. There is no reason why this cannot happen in health care. For example, Internet Protocols (TCP/IP) were adopted across the world; exchange standards for data sharing among banks, clients and financial services; and cybersecurity standards for aviation have enabled globalised control of air transportation.

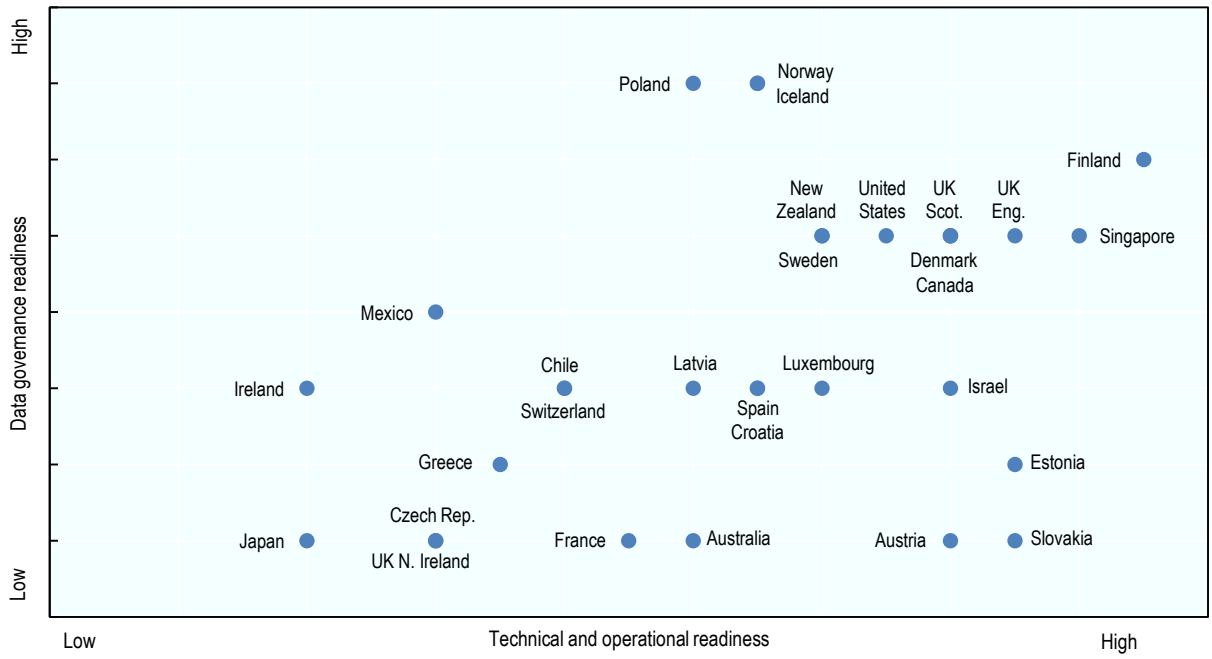
  The bespoke approach that has been applied to health data development, on the other hand, causes health care organisations, systems and countries to speak 'different data languages' – a major barrier to modernising health systems and achieving similar economic and social benefits as have been realised in other sectors. The inconsistency of health data is also a major reason for the commodification of personal health data, with profits to be made from aggregating, cleaning and harmonising large datasets.

  There is some progress on developing common data terminology standards that harmonise data and enable their pooling, with a number of public and private sector initiatives currently under way. The EU has established policy to support the sharing of health data across borders, including work toward fully interoperable electronic records for research, diagnosis, treatment and disease prevention, and policies promoting effective sharing of genomic datasets to advance personalised medicine. The European Health Data and Evidence Network (EHDEN) is a shared public/private investment in developing an approach to standardising a wide range of health data. EHDEN to create a common data model to facilitate health statistics, monitoring and research undertaken by governments, universities and the private sector entities, such as for pharmaceutical research (EHDEN, 2019[70]). Global private sector initiatives such as the DaVinci project and FHIR are also aiming to establish common approaches and standards to enable the sharing of health data across borders.[16]

  These initiatives should be welcomed. But there is a risk that their multitude exacerbates the very challenge they are trying to solve. The work that has taken place to date needs to be consolidated, and countries should agree and reach consensus on standards for the growing range of data relevant to health that can and should be shared across borders. This effort requires global coordination involving a range of stakeholders in both the public and private sectors. An international organisation such as the WHO or the OECD could facilitate this needed collaborative work.

- *Ensuring that data are available broadly, securely and at low cost.* In contrast to data that are generated as a pure by-product of health care delivery or other human activities, access to some types of data whose generation entails costs may need to be subject to exclusivity through intellectual property rights. Policy on intellectual property, 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[1]). This relies on solid data governance and policy frameworks (see Section 1.5.2).

Figure 1.10. Some countries are ready to deploy EHR data for secondary purposes



Source: OECD Survey of Electronic Health Record System Development and Use, 2016; Oderkirk (2017[34]), Readiness of electronic health record systems to contribute to national health information and research"", https://dx.doi.org/10.1787/9e296bf3-en.

1.4.5. The right incentives play a major part, and rely on policies and institutions

Transformation, especially in complex systems, does not occur organically. Transformation only occurs under the right environment, when the right incentives are aligned. The first industrial revolution began in Britain not because of the invention of steam power, which had existed for decades. Rather, it was the high cost of labour and low cost of energy (coal) in Britain at end of the 18th century (Allen, 2011[71]). Steam power was integrated into the industrial system – or rather the industrial system was reconfigured to make the most of steam technology – only when it made economic sense to do so. When it was, it transformed the industrial production methods and entire economies in the process.

Health is a highly regulated sector and the incentives, which may be financial or not, throughout health systems are heavily influenced by policy. Policies and their enabling institutions are therefore pivotal in driving a digital transformation. However, it can be argued that current policy settings create incentives that do not promote the intelligent use of data and digital technology. This dissonance may be a core reason for the slow pace of digital transformation in the health sector. It highlights the importance of re-designing the policy and institutional settings that underpin how a health system functions – and that digital transformation is not possible without institutional reform.

New payment models (see Section 1.3.6) can illustrate this issue. Remuneration plays a key part in dictating individual and institutional behaviour. While data infrastructure and digital technology provide the tools, uptake will be slow without the deeper institutional and policy changes. For example, continuing to pay for individual fragments of care will do little to stimulate the adoption of technologies that can make service delivery more people-centred materials (Murdoch and Detsky, 2013[11]). Alignment of budgetary and expenditure accountability across organisations, regions or care settings is required, and providers and provider organisation would need to move towards a team-based approach of delivering care across settings. Such fundamental changes in practice and behaviour requires tailored incentives.

Payers also need to ensure that integration of new technology does not destabilise existing services as this may compromise clinical safety as well as trust and morale among patients and providers. NHS England, for example, is in the process of updating its contracting and payment rules for primary care to address emerging challenges and embrace opportunities of digital technology because a growing share of primary care activity occurs on digital platforms. The new payment system will account for the 'mix' of ICT-based and face-to-face contacts. While this can only be achieved by using various forms of available data, reporting of data on the costs of digital provision in general practice is a critical part of the new model. This will enable to enable close monitoring, and continuous development of payment rules (NHS England, 2018[72]).

Harmonised information systems, appropriate skills and attitudes, ethical frameworks and engaged stakeholders provide the possibility for a positive digital transformation. But progress will be slow without a significant overhaul of existing institutional and policy frameworks that steer health system behaviour.

1.5. A focus on strategy, governance and capacity will require sustained commitment but also deliver a healthy return on investment

A digital transformation is not an end in itself. It is a means to achieving policy objectives such as better health outcomes, equity and financial sustainability. If anything, the emergence of digital technology and its potential uses have highlighted some long-standing problems that impede *any* reform – digital or other – in achieving these goals. As highlighted in the previous section, digital transformation is therefore best seen as part of a more fundamental transformation of institutions that govern how health systems function.

This section outlines a tractable approach to bring about the transformation that will see data and digital technology put to work intelligently and productively. The objective is to create an enabling policy environment. Policy makers to focus on three related but sequential elements: strategy, governance and capacity. In most cases this requires additional investment or, at a minimum, a re-allocation of existing resources towards capacity-building elements. If executed well, the expected returns are considerable.

1.5.1. An overarching strategy is the foundation

All countries that are on track to harness the opportunities of health data and digital technology have one thing in common: an overarching digital strategy. This begins with the acknowledgement that data and digital technologies are a valuable resource to advancing human health, and a vision of how this resource can be used. Clearly articulating a set of principles that align with broader health system objectives can convey a number of cross-cutting advantages to driving a digital transformation at all levels of a health system. This allows better planning and execution of the necessary changes, as well as adaptation of organisational structures, institutions and workflows.

For example, in Sweden successive digital health strategies have been in place since 2006 (Swedish Ministry of Health and Social Affairs; SALAR, 2016[73]). The latest strategy was jointly developed by the national government and the Swedish Association of Local Authorities and Regions (SALAR) and endorsed in 2016 to guide the digital transformation through to 2025. The goal of the strategy is 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" (ibid, p.3). The Swedish strategy comprises three streams:

1. increasing digital information exchange, both between different public authorities and with citizens, while safeguarding privacy and data security;
2. advancing semantic interoperability of data in the health system; and
3. ensuring technical interoperability of ICT systems.

As shown previously, Sweden reports near-universal use of electronic medical records in primary care and hospitals, the second highest rate of availability and linkage of key health datasets for secondary use and the use of routine data for monitoring medicine use and expenditure. The proportion of people who access health-related information online in Sweden has increased from less than 30% in 2007 to more than 65% in 2017, which is among the highest shares across OECD countries.

Strategy is the first step to address the key problem of fragmentation

A good strategy can promote coherence across the health system silos. For example, in Israel, the digital strategy sets the foundation for cooperation between private and public entities, with the public sector setting standards for ICT and data and the private sector developing and delivering innovative digital tools. Nearly the entire Israeli population is covered by EMRs developed independently by the four Israeli health maintenance organisations (HMOs) that provide mandatory health care coverage. A digital health strategy helps working towards interoperability of these systems, creating unified EHRs that can be shared across all health and social care providers and be re-used to support research and other purposes.

A single, national strategy is particularly critical in countries with a federated system of government and/or corporatist social health insurance systems. In these situations, understanding and co-operation between states, territories and provinces, and self-governing entities is a make-or-break feature of a digital transformation at a national scale.

In Canada, for example, the federal government established Canada Health Infoway in 2001, an independent and not-for-profit organisation, 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. Federal funding is channelled to local projects through Infoway, which allows the federal government to influence the design of technical solutions and encourage provinces to implement ICT that is interoperable. However, the fragmentation of legacy systems and interoperability between provinces, and among individual health authorities between provinces, continue to be a challenge in Canada.

Cross-sectoral, whole-of government strategies appear to be most effective

The aforementioned Swedish digital health strategy builds on earlier progress of e-government in sectors outside of health care, which has improved significantly the communication between government entities and citizens and the responsiveness of such entities. The strategy covers the full range of social services and recognises that health care is an integral part, but not the only means of achieving societal goals, such as allowing everyone to live independently while participating in social life. The Swedish strategy explicitly prioritises marginalised and underserved groups to promote equitable distribution of gains from digitalisation.

Developing an overarching digital strategy also requires broad stakeholder consultation, most notably with the public. For example, in Australia, the Australian Digital Health Agency conducted a national consultation with clinicians, health care providers, payers and the general public to support the development of the national digital health strategy. The strategy was launched in 2017, and publicly supported by associations of health professionals, private sector trade associations and consumer representatives (Australian Digital Health Agency, 2017[74]).

Within the Israeli strategy, broad consultations are held to identify challenges in the health care system that are amenable to digital solutions. Tenders are then opened to provide funding to IT firms, and in particular local start-ups, to develop innovative solutions. Broad commitment to a strategy paves the way for creating the policy and technical infrastructure that enables putting data to work. Involving all relevant stakeholders is also the first critical step in establishing good governance and trust.

1.5.2. Good data governance can develop the key element of trust

Governance, in the context discussed here, means creating a policy environment that enables digital technology to be deployed, and knowledge to be extracted from data while at the same time ensuring that this is done securely, and in a way that respects individuals' privacy and their preferences. Governance includes technical, legal and policy levers. In most countries, the key elements of governance in the context of data and digital technology such as privacy legislation were developed and instituted last century. The HIPAA Act, for example, which sets out the data privacy and security provisions for safeguarding medical information in the United States, was enacted in 1996.

The Recommendation of the OECD Council on Health Data Governance, welcomed by Health Ministers of OECD countries in 2017, sets out the fundamental elements countries need to manage and use personal health data for purposes that serve the public interest, while protecting privacy and ensuring data security. (OECD, 2019[75]). The Recommendation's twelve mechanisms can be grouped into categories relating to technical, policy and communication requirements. Implementing the Recommendation will go some way in addressing the barriers of using data (and digital technology) and putting these to work for positive system transformation.

For example, the Recommendation provides clarity for health system leaders to communicate the benefits of a digital transformation. This enables an informed public discourse that encompasses the opportunities as well as the risks, which include, of course, the benefits foregone of *not* putting data to work. It also dispels the notion of a trade-off between data protection and their use. The Recommendation also contains technical requirements to ensure efficient data exchange can occur, and necessitates the institution of strict cybersecurity policies and processes. Perhaps most importantly, it is designed to promote harmonisation of policies and legal requirements governing access, management and use of personal health data within and across countries. Such 'policy interoperability' is critical in pooling of large datasets for public policy purposes.

A key purpose of governance is to establish trust

Lack of trust among patients, the public, data custodians and other stakeholders in how data are used and protected is a major hindrance to getting more out of data and the technologies that generate, and depend on them.

Personal health data are very sensitive, and privacy is understandably one of the most often cited issues in using them. But by generating useful knowledge, using personal health data can also make a great contribution to human health and welfare. Evidence suggests that patients and citizens are actually positively disposed to their data being used as long as the data are kept secure and are used for purposes that benefit society. Strong cybersecurity is therefore an important component of trust and data governance. Technologies such as blockchain can be deployed, but it is also important to ensure that personnel tasked with ensuring data security and integrity have the requisite skills and expertise.

It also very important to communicate the benefits of using data – as well as the risks of not using them. Transparency about when data are used, for what purpose and by whom is important. Equally, transparency, leadership and decisive action when breaches do occur. This is often lacking, and creates another barrier to better uses of data for public benefit.

Governance across sectors and across borders

Good data governance enables the health system work with the commercial sector to achieve common objectives, both in terms of processing and managing health data as well as developing digital solutions that advance health and wellbeing. It also encourages the development of common taxonomies and data standards to encourage interoperability of digital products and platforms both within and across countries.

Some countries are moving towards better engagement with the technology developers. The Israeli Ministry, for example, employs so-called Challenge Tenders. These specify a policy or technical problem that needs be solved without defining the nature or specifications of the solution. Companies are challenged to come up with the solutions to the proposed problems. This flexible approach is particularly suited to digital technologies.

In the United States, the ONC has created a prizes and challenges program to engage technology developers and incentivize digital innovation in health. The competitions focus on innovations that support: 1) ONC's aim to clear hurdles related to the achievement of widespread adoption and interoperability; 2) ONC and HHS programs and programmatic goals; and 3) the achievement of a nationwide health IT system that improves quality, safety, and/or efficiency of health care.

The European Union is investing in elements of a pan-European information system to enable biomedical research, health system surveillance and clinical information exchange, as well as improving patients' access to quality care and their care experience. Work is underway in areas such as data infrastructure for health system performance monitoring and research; infrastructure for clinician collaboration in patient treatment decisions and research; and data and infrastructure for biomedical and genomic research.

For example, the EU-funded CEPHOS Link project applied a common protocol to administrative data from national health care databases in six European countries (Austria, Finland, Italy, Norway, Romania, Slovenia) – all with different health care systems and varying data collection methods – to estimate psychiatric rehospitalisation rates and their predictors (Katschnig and Strassmayr, 2017[76]). The project involved data acquisition, management, quality, interoperability, privacy protection and linkage methods and included local and pooled data analyses, performed with statistical methods and innovative dynamic modelling approaches. A number of European initiatives are under way to facilitate more in-depth research based on pooled data, including research based on the human genome. A significant part of these efforts concerns harmonising data collection and exchange standards across borders.

In addition to technical interoperability, alignment of policy and governance frameworks is also essential. If regulations regarding privacy, transparency and control over data are not aligned between countries, common data languages will do little to advance putting data to work on a global scale. The OECD Council Recommendation provides a mechanism to harmonise national data policy and governance frameworks that goes some way to create a global information ecosystem that can extract knowledge from large pools of health data but do so securely and in accordance with agreed regulatory principles (OECD, 2019[75]).

1.5.3. Building capacity for a digital transformation requires investment

Strategy and governance are very important. But without the institutional, operational and policy capacity to extract knowledge from data and then deploy this knowledge effectively, any potential for positive system transformation will not be realised.

Capacity building covers the barriers and enablers discussed in Section 1.4. It also means ensuring that the underlying infrastructure is in place to enable data to be put to work effectively. This applies to hardware as well as software and other intangible products to generate, store, link and analyse data.

Institutional capacity must not be neglected. The best digital strategies, governance frameworks and skilled workforce will not ensure that knowledge extracted from data is applied to meet policy objectives. Existing policies, processes and workflows need to be reformed in a way that enables data-driven knowledge to be applied most effectively. It means equipping agencies and organisation with access to data and the ability to extract knowledge from them. It also means arming these institutions with the necessary 'teeth' to act on the knowledge generated. The roles, responsibilities and powers of regulators, payers, public health authorities and other health system actors must be aligned with what a data-driven approach can do.

This includes re-thinking the prevailing macro-policy settings and institutions that dictate how things are done in health. This concerns not just remuneration, but also how regulation is set and enforced or how performance is evaluated. Policy makers must think about lowering the barriers for smart deployment of digital technologies and intelligent uses of data that can help achieve policy objectives – from better quality care, to using scarce resources more efficiently at all levels of the system.

Targeted and sustained investment is needed

The complexity – and cost – of successfully implementing the actions discussed above requires sustained investment. OECD countries typically invest considerably fewer resources than other sectors on information systems (OECD/WHO/World Bank Group, 2018[25]). This is surprising for an information-intensive industry. More targeted investment is certainly needed to better manage data and information. However, in most cases the investment should be principally targeted at institutional and policy reforms, skills and expertise of the workforce, and demand-side capacity. This is because the majority of costs of implementing a data-driven innovations and digital technologies in the health sector are tied up in the planning, preparing personnel and redesigning process. Capital expenditure can represent only about a quarter of the overall implementation costs. The dominance of costs related to capacity-building and workflow redesign align with the long-standing findings on digital technology and its role in productivity (Brynjolfsson and Hitt, 1998[77]). Moreover, 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[78]).

The most pressing areas for investment are human capital and expertise, adapting processes and workflows, and – critically – solid policy and governance frameworks to ensure benefits are maximised while risks are managed. Investment is required within communities, in the health workforce and in the policy capacity to turn knowledge into meaningful action.

1.5.4. But the returns can be considerable

Digital technology is general-purpose, meaning that it can penetrate all aspects and activities of an organisation or endeavour (Brynjolfsson, Rock and Syverson, 2019[27]). Rather than creating new things to do (a main driver of spending growth in health), data and digital technology are particularly suited to improve virtually every existing process and activity in an organisation, industry or sector (see Section 1.2.2). The resulting efficiencies and productivity gains of small and incremental as well as large innovations are considerable but also difficult to quantify *ex ante*. For example, thirty years ago it would have been impossible to predict the myriad ways that the internet would transform the global economy.

Capturing the macroeconomic effects of a fundamental system transformation, the costs and benefits within and outside the health system, is a challenging task. Suitable economic models are yet to be developed (Marino and Lorenzoni, 2019[13]). Nevertheless, by making virtually every aspect of what a health system does more efficient and productive, the expected health and economic dividends of a digital transformation in health are considerable – even when factoring in increased investment The dividend can be broken into two parts:

1. reducing wasteful and inefficient practices, redundant processes and clinical harm, and
2. addressing unmet health need, improving public health and enabling access to safer and better therapies.

Reducing wasteful and inefficient practices

As described previously, approximately a fifth of health care expenditure generate no benefit to people and populations and, sometimes, their effects are even detrimental (OECD, 2017[29]). Across OECD health systems, 20% of waste amounts to over USD 1.3 trillion per year. However, the health sector in some

countries is considerably more inefficient and wasteful, with pricing failure, administrative complexity, and fraud among the key drivers of (Shrank, Rogstad and Parekh, 2019[79]).

Leveraging data and digital technologies can help reduce this waste in the ways outlined in Section 1.3 and the remainder of this report. Even a relatively modest reduction of 30% would amount to approximately USD 400 billion per year across OECD countries. This would be principally achieved by improving clinical, operational and administrative efficiency, and removing redundant activities and wasteful practices.

Improving health outcomes

More intelligent use of data and digital technologies can also improve public health and address unmet health need more effectively. Harnessing real-world-data can also enable the continued development of safer and better treatments, and help integrate them into service delivery in a sustainable way. Such improvements can also deliver considerable economic benefits through healthier and more productive populations. Some of these returns, would be spent on breakthrough biomedical technologies. On the other hand, more agile and outcome-driven remuneration of treatments and services across an entire health system could deliver much improved value and efficiency.

The combining economic benefits of putting data and digital technology to work in health to improve efficiency, reduce waste, address unmet need and improve population health care could amount to USD 600 billion each year This is equates roughly to the GDP of Poland, and represents about 8% of current health expenditure across OECD countries. It is a conservative estimate and, compared to existing projections, is not far-fetched.

- Projected savings generated by leveraging digital technology and data in the health sector have been as high as 17% of health care expenditure (Kayyali and Van Kuiken, 2013[80]).
- It is estimated that digital technology in National Health Service (NHS) of the United Kingdom has the potential to deliver efficiencies amounting to of GBP 13 billion a year (OECD, 2017[12]).
- NHS data alone have been valued at GBP 9.6 billion per annum, the value generated principally by the new knowledge and insights that could be unlocked from them (EY, 2019[81]). This is approximately 5% of health expenditure in the United Kingdom (OECD, 2019[82]).
- Interoperability between electronic data platforms in the United States is said to potentially deliver annual savings approaching USD 100 billion (OECD, 2017[12]).

Based on these figures, additional investment equivalent to 2-4% of health care expenditure to promote more intelligent use of data for information and knowledge (effectively a doubling of current investment levels)[17] could equate to a healthy return of approximately 3 to 1. In some cases, simply redirecting existing resources towards the key areas described above – capacity building and data governance – could achieve the expected returns.

1.6. Conclusion

The explosion of data and digital technology has led to significant improvements, value and surpluses in a range of sectors. In the health sector, the potential health and societal benefits of using data and digital technologies are profound. The information and knowledge derived from existing data can be used to deliver not only better care, better public health and faster access to better treatments but also more efficient management and administration of complex health systems. A digital transformation can help deliver better health more efficiently and equitably.

However, health lags far behind other sectors in this regard. But the barriers to catching up are not technological, but institutional and organisational. The data as well as the technologies and infrastructure to use them are mostly there. Failing to exploit them is costly and wasteful. Indeed, the difficulties of

achieving a true digital transformation has served to highlight structural problems – such as fragmentation and silos – that pre-date the digital era and have hindered progress for decades. These cannot be fixed by simply digitising what health systems do, It needs an overhaul of policy settings and institutions. In a sense, digital technology is a Trojan horse for a more badly needed deeper transformation in health. Instituting such a transformation is a political choice. It will not happen without leadership and policy action.

In order to progress, countries must invest in strategy, governance as well as institutional and operational capacity. Increasing current investment, or in some cases simply re-allocating existing resources, targeted at improving governance and capacity can promote a digital transformation and deliver a healthy return approaching 10% of what OECD countries currently spend on health care.

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Notes

[1] The systems and infrastructure that store data and the software that enables secure sharing all have significant costs. However, theses costs are distributed across all of the instances when the data are used and re-used. The more often this occurs the lower the *marginal* cost. It is also true that re-using data other analyses requires strong governance mechanisms that prevent unauthorised use and ensure security, privacy and consent. Governance is not cost-free but, again, the costs diminish at the margin and, as illustrated in this report, the returns can be considerable.

[2] A public good is something that is *non-rivalrous* (use by one individual does not reduce availability to others or the good can be effectively consumed simultaneously by more than one person) and *non-excludable* (individuals cannot be excluded from its use) (Cowen, n.d.[83]). Classic examples of public goods are lighthouses and national defence forces. Data fulfil the non-rivalry criterion. However, they are frequently controlled by organisations, firms and individuals. This means that their non-excludability relies on public policy, specifically data regulation and governance. The importance of governance is a key theme of this chapter and this report.

[3] In this report, the term 'health system' describes how the provision of services that aim to achieve health policy objectives is organised at national level. This includes organisations, agencies and institutions that deliver health care and medical services as well those responsible for public health interventions and policies. Health systems can also refer to sub-national system or network of health service providers, but the distinction is specified where relevant in this report.

[4] See Chapter 6 (Data without borders) for further discussion of this issue.

[5] See Chapter 5 (Box 5.1) for a definition of big data.

[6] See Chapter 6 for further discussion on biomedical technology and routine data.

[7] The reality of these predictions is addressed in Chapter 4 of this report.

[8] An electronic medical record (EMR) – sometimes called an Electronic Patient Record – is a computerized medical record for individuals created in a service or an organisation that delivers care, e.g. hospital, physician's office or long-term care facility. EMRs are typically unique to the provider or organisation, and allow storage, retrieval and modification of its patient records. An electronic health record (EHR) is a longitudinal digital record that contains a history of all contact with the health system for an individual regardless of the settings, service and organisation at which the contact took place. This can be achieved by either having one EHR across all settings and organisations in a health system ('one patient - one record'), or provide a platform that can link multiple EMRs so that the information can be shared between settings and relevant agencies that use the data. Source: OECD survey on secondary use of EHR data, 2016 (Oderkirk, 2017[34]).

[9] For more detail on better service delivery and people-centred care, see Chapters 2 and 3.

[10] More detail on risk-stratification is provided in Chapters 2 and 8.

[11] More detail on managing biomedical technology using available data is provided in Chapter 7.

[12] More detailed discussion on public health and Big Data can be found in Chapters 5 and 8.

[13] A more detailed discussion on harnessing data for health system governance and stewardship can be found in Chapter 8.

[14] More detail on potential funding models is provided in Chapter 8.

[15] More detail is provided in Chapter 4.

[16] More detail on approaches to harmonise health data is provided in Chapter 6.

[17] Based on estimates that 2-4% of health expenditure in developed countries is invested in information systems.

2 New ways of delivering care for better outcomes

Martin Wenzl

Health care delivery supported by information and communications technology (ICT) has great potential to make health systems more effective in improving health, more equitable and more efficient. ICT and data can be harnessed to redesign health services according to needs and to deliver services in an integrated and people-centred way. The increasing number of patients with complex needs in OECD countries stand to gain the most from new models of care delivery. ICT can help identify such patients, inform them about their own health and care, improve communication and coordination between them and their providers, increase the accuracy of diagnoses and clinical decision-making, and help monitor their health remotely and deliver appropriate services across geographical distances. However, without an overarching architecture that ensures that new tools are interoperable and can be integrated with existing information systems, ICT may entrench and even exacerbate fragmentation and inequity. Many OECD countries still appear to be far from realising this potential for transforming care delivery.

2.1. Introduction

The prevailing models of health care delivery are inflexible, fragmented and specialty-based. In the context of changing disease patterns, financial pressure and emerging technologies, such models cannot be relied on to serve population health needs sustainably. Future services must be tailored to patient needs and delivered in an integrated manner, targeting the right patients at the right time, while delivering a positive experience for patients as well as providers.

This chapter addresses the central issue of how to use information and communication technology (ICT) to improve health care delivery for achieving better care quality and health outcomes.[1] Focusing on people with complex health needs, it outlines the opportunities and risks as well as potential costs of increased use of ICT for improving care delivery.

ICT improves the capacity for using data to generate, manage and share valuable information much more effectively and at a lower cost. If used appropriately, ICT can help health systems achieve their overarching goals by adopting better and data-driven ways of delivering care that provide the right and high-quality health services to the right people at the right time.

However, there are no guarantees that greater adoption of ICT will automatically meet policy objectives. Implementing ICT across entire health systems in a way that improves effectiveness, reduces health disparities and achieves both sustainably and efficiently is a major policy challenge. Nor is greater penetration of ICT itself sufficient to improve the performance of health systems. Ultimately, digital technologies should not merely be used to digitise analogue processes and services, but as an opportunity to fundamentally rethink and reorganise processes, workflows and services in a way that addresses peoples' health needs and improves outcomes sustainably (OECD, 2019[1]). This requires a concerted effort led by policy makers, health system managers and health professionals and that is supported by all stakeholders, including patients.

For the purpose of this Chapter, *care delivery* refers to the complete set of modalities in which health care is delivered to patients, including the physical setting, the health care providers involved, the mode of interaction between patients and professionals as well as among the various professionals and provider institutions involved in care, attendant remuneration mechanisms for provider institutions and professionals, and any supporting tools used, in particular ICT.

Care delivery can be described on varying scales. Distinct models of care delivery can be found in small-scale and local pilot initiatives or can, once matured and broadly implemented, be the prevailing way of providing care in a health system. An entire level of care (such as primary care) can be organised according to a given model of care delivery, as can be care for a specific disease (such as disease management for diabetes or other chronic conditions) or care for a specific patient group (such as case management for elderly patients with complex needs).

For example, in many health systems solo-practice by general practitioners (GPs) has traditionally been a prevailing model of delivering primary care. In this model, patients would make appointments when they felt ill and would see their GP on an episodic basis to receive treatments and individual referrals to other providers of care. GPs would mainly work independently from other professionals, be paid on a fee-for-service basis and provide services in a reactive manner.

More recently, the primary care has started relying on digital technology, replacing or complementing face-to-face consultations with automated triage and tele-medicine, allowing for remote contacts between patients and physicians. In some health systems, primary care is increasingly provided by multi-disciplinary group practices. These are newer models of primary care delivery.

The increasing prevalence of chronic diseases has made disease and case management more common as distinct models of care delivery for patients with a single or multiple chronic diseases. In such models, the provision of care involves not only episodic consultations but also proactive identification of patients,

for example through screening, broad assessments of their health status and their care needs, and their continued and proactive monitoring, often by a dedicated case manager, to respond to changes in need. Care delivery is often supported by ICT systems to exchange information among professionals and with patients and fee-for-service payments are often replaced with capitated or bundled payments.

This chapter comprises three main sections. Section 2.2 shows that people with complex health needs are the greatest potential beneficiaries of harnessing ICT in care delivery and shows how data can help *design and target* needs-based health services. Section 2.3 discusses how ICT, and the use of data generated by such technology, can improve the process of health care *delivery* to complex patients. Section 2.4 examines why successful new ways of delivering care are not often scaled and sustained, and how this can be addressed. Content of this Chapter is based on the published literature but also relies heavily on examples and case studies of care delivery in health systems of OECD countries.

2.2. Using data to design better health services and target them more accurately

Patients with complex needs, such as those with multiple chronic diseases, stand to gain most from harnessing ICT and in the delivery of care. Secondary use of data is the key to *remodelling services around patient needs*. But integrating care for complex patients can also be resource intensive and costly. Integrated care therefore needs to be personalised and targeted accurately at those people who can benefit most.

2.2.1. Data present an opportunity to sustainably improve care for the growing number of patients with complex health needs

Chronic diseases are now the main causes of mortality and morbidity in OECD countries. Increasing shares of populations are affected by multi-morbidity, the presence of several concomitant chronic illnesses (physical and mental) in the same person. Overall estimates of the prevalence of multi-morbidity across OECD countries are not available. However, country-specific surveys and epidemiological studies suggest that prevalence is high and increasing. In Ontario, for example, the prevalence of multi-morbidity increased by 40% between 2003 and 2009 (Koné Pefoyo et al., 2015[2]). Estimates suggest that multi-morbidity may now affect approximately one in three adults in Ontario, one in four adults in Australia and one in five adults in Denmark (Mondor et al., 2018[3]; Schiøtz et al., 2017[4]; AIHW, 2018[5]). In a sample of ten European countries,[2] the prevalence of multi-morbidity among people aged 50 and above has been estimated to have increased from 38% in 2007 to 42% in 2015 (Palladino et al., 2019[6]).

Current ways of delivering care are ill-suited to emerging health needs

Health care is often provided inflexibly in a fragmented and specialty-based way. This is particularly ill-suited for serving the increasing number of people with multi-morbidity and complex needs in OECD countries.

People with multi-morbidity manage a high volume of information, interactions with various providers, and self-care tasks; they need to coordinate, synthesise, and reconcile health information from multiple sources and about different diseases; and their position at the intersection of multiple health issues requires self-advocacy and expertise. Multi-morbidity also often occurs among the elderly, the disabled or people in lower socio-economic classes, who might find it particularly difficult to *navigate* current health systems and accomplish all of these tasks related to managing their health. In Denmark, for example, multi-morbidity affects every other person older than 65 (Schiøtz et al., 2017[4]). Among people with lower secondary education only, the prevalence is double that among people with postgraduate education (ibid.). The co-occurrence of multi-morbidity with difficult socio-economic circumstances make the care needs of such population groups particularly complex.

ICT and data present an opportunity to make care more effective and efficient

People with complex needs account for a disproportionate share of total health care utilisation and expenditure in OECD countries. In United States, for example, health care costs of people with three or more chronic conditions are almost twice as high as in the average adult population and costs of people with three or more chronic conditions and disability are more than four times higher (Hayes et al., 2016[7]).

A complexity-based stratification of the population of the Spanish region of Catalonia (see Chapter 8 on system governance, stewardship and resource allocation for further details) found that, compared to people below the median on the complexity scale, people in the top percentile of the complexity score were 27 times more likely to have an emergency hospital admission (31.9% vs. 1.2%), had 15 times the number of primary care consultations (31 consultations on average per person and year vs. 2.1) and 61 times the pharmaceutical expenditure (EUR 1 394 on average per person and year vs. EUR 23) (Monterde, Vela and Clèries, 2016[8]). A recent cost-of illness study in New Zealand found that co-morbidity resulted in greater health care expenditure than the expected sum of the present conditions in isolation, with 24% of all health care expenditure attributed to this super-additive feature of complexity (Blakely et al., 2019[9]).

The enhanced use of data and deployment of the knowledge that can be generated from them present a great opportunity for improving the care for people with complex health needs. Through its ability to generate and analyse vast amounts of data, ICT can help improve care for these people in multiple ways, as described below. Effective uses of ICT and data for improving care for people with complex needs are necessary to promote financial sustainability of health systems through deploying services where they generate the most benefit, which drives system efficiency. They also increase efficiency by preventing more costly future service use, such as emergency room visits and hospital admissions.

However, needs-based care delivery does not necessarily imply cost savings; it can also result in *increased* secondary and tertiary care utilisation and higher aggregate costs, in particular in the short and medium term. This was the case, for example, in the *Personalised Integrated Care Programme* in the United Kingdom, a pilot project of personalised support to older people who are at risk of a future emergency admission. While the scheme delivered positive outcomes as reported by patients and staff, it resulted in a rise in hospital activity (and costs) for enrolled participants in the 16 months following implementation. The most likely reason for this increase is that participation led to previously unidentified health needs being addressed (Nuffield Trust, 2019[10]). It is possible, however, that this increased hospital activity prevented more serious morbidity in the future and, in some cases, perhaps premature death (but longer-term effects were not examined). It may therefore translate to lower future expenditure, efficiency gains and value for money. This serves as a reminder that expenditure should ultimately be viewed in the context of long-term health outcomes and across budget silos.

2.2.2. Personalising care with better information

Secondary use of large datasets can also be a key source of information for redesigning services and tailoring distinct interventions to individual patient needs. *Personalised* care concerns tailoring care pathways to individual needs and preferences and can also only be achieved through effective use of routine data.[3] Integrated care for patients with complex needs can benefit particularly from data analytics for personalisation.

For example, electronic data from a range of sources can enable modelling of complex care pathways and developing treatment guidelines that take into account interactions between co-morbidities, complicating factors and distinct treatments. Considering diseases in isolation is a widely recognised shortcoming of existing paradigms in medical research and the resulting management of chronic diseases (Tillmann et al., 2015[11]). Many randomised controlled trials (RCTs), which are the current mainstay of evidence generation in medicine, *explicitly exclude* complex patients to increase the likelihood of isolating the effect of the intervention under investigation despite the fact that people in the general population are more likely to be

affected by multi-morbidity than by any single chronic disease. Deriving medical knowledge only from prospective studies with limited sample sizes, including RCTs, necessarily misses an opportunity to generate knowledge from the data on the majority of the population that is treated in *routine* outside of prospective studies (also see Chapter 7 on biomedical technologies).

Ushering in 'System Medicine' with modern data analytics

The term *system medicine* has been proposed to describe a new paradigm in which the development and selection of treatment strategies for patients with complex diseases is based on data-driven analysis of the human body as a complex system of interacting biological process that determine an individual's level of health (and disease) (Gietzelt et al., 2016[12]; Tillmann et al., 2015[11]).

ICT allows for combining data from various sources and for analysing large amounts of data to model *real-life* disease trajectories, disease interactions and effects of medical interventions. Only once patient complexity is better understood can this knowledge be applied in the routine delivery of care for complex patients. For example, clinical decision aids can only provide appropriate and personalised treatment guidelines for patients with multi-morbidity once the interactions of diseases present in the same patient and interactions of corresponding treatments have been studied and are thoroughly understood.

Even if medical research may still be a long way from a true system medicine approach, early examples of how large volumes of electronic data can be used to generate knowledge of disease complexity are already available. The Spanish GMA system (see Chapter 8 on system governance, stewardship and resource allocation) has recently also been used in Catalonia for a number of epidemiologic studies that assessed, for example, the co-morbidity burden, complexity and resource use of patient populations with specific index diseases.[4] Such studies help identify patient subgroups that require specific interventions and inform the improvement of their care.

With increased computational power, new techniques can be used to analyse large routine datasets. Data mining, for example, allows medical research to not only take a hypothesis-driven but also a data-driven approach Phinney et al. (2017[13]), for example, show that data mining techniques can identify patient characteristics associated with a high risk of health deterioration simply by recognition of patterns in the data. Results from such analyses can support the delivery of health care but also encourage additional hypothesis-driven research: while algorithmic data mining can, in this example, identify *who* is at risk of health deterioration, only more traditional hypothesis-driven research can go further and answer the question of *why* a set of patient characteristics are associated with health deterioration (ibid.). Artificial intelligence can be deployed for making computers more accurate in predicting outcomes, such as hospital readmission, the occurrence of complications or death by feeding them data, and allow for the corresponding adaptation of interventions and care delivery (Topol, 2019[14]; JASON, 2018[15]).

Making the necessary data available to unlock their knowledge potential

Using data analytics for greater personalisation and needs-based redesign of services requires that the necessary data are accessible and available for such purposes. Because of the properties of electronic data, which allow for their duplication and sharing across geographic distances at very low marginal costs, databases to support research can be created relatively cheaply through extraction and linkage of data from routine sources (Kannan et al., 2017[16]). While data extraction, and especially cleaning and curating them for analysis, can be costly, such secondary use is likely much cheaper than original data collection for each research purpose. Registries, for example, can be developed virtually by pooling data from other, existing sources such as health records, prescriptions hospital admissions data. New Zealand has created such a 'virtual' national registry of diabetic patients as a useful resource for policy makers, providers and patients (see Chapter 8 on system governance, stewardship and resource allocation).

The combination of data generated in routine health care with other datasets, in particular genomic data, allows for unlocking new knowledge that can help personalise treatments and make them more effective. Agarwala et al. (2018[17]), for example, show how gaps in knowledge underlying the selection of treatments for cancer can be filled by analysis of a combination of longitudinal EHR data from cancer centres with genomic datasets. Using the treatment response and health outcomes achieved in large samples of patients together with information on genetic characteristics of tumour mutations significantly increases the likelihood that the most appropriate treatment combination is selected for any given patient from the plethora of options available (ibid.).

In conclusion, Agarwala et al. (2018[17]) also highlight, however, that accessing dispersed datasets and linking them in accordance with data privacy requirements is very challenging. More integrated information infrastructure and continuous data sharing among providers and laboratories would enable the unlocking of information contained in such data (ibid.). This requires data governance and policy frameworks that manage privacy risk while permitting secondary uses of personal health data for public benefit.

Integration of genomic and other –*omics* data into care pathway design is an emerging frontier. Geisinger, a private health insurer and integrated provider network in Pennsylvania and New Jersey in the United States, has used data-based patient pathways in the past to reduce unexplained variation in clinical practice and improve the quality of care. Since 2014, Geisinger integrates genomic information into the EHRs of patients who consented to having their DNA sequenced (see Box 2.1). This information is used to personalise care. For patients that are insured with Geisinger Health Plan, clinical exome sequencing is included in benefit packages at no additional cost and any care recommended as a result of a pathogenic variant found in analysis of the sequence is considered medically necessary, and therefore covered per the terms of the individual's specific benefit package (Williams et al., 2018[18]).

Box 2.1. Integrating genomic information into clinical care at Geisinger in the United States

Geisinger is a private health insurer and integrated provider network in Pennsylvania and New Jersey, which serves a population of more than 4 million people with about 1.5 million patient visits annually. About one-third of patients are also insured with Geisinger.

To improve care and health outcomes through earlier diagnoses and personalisation of care, Geisinger launched the MyCode biorepository of genomic patient data in 2007. Data was initially collected for research purposes and later to be included in EHRs and used in the delivery of health care. Since 2014 MyCode conducts whole exome sequencing and genotyping on collected samples to capture the part of the genome containing the most clinically relevant information. Geisinger patients are enrolled in MyCode irrespective of health status. So far, about 200 000 patients consented to enrolment, representing about 90% of patients who have been offered enrolment.

Patient DNA is sequenced in a laboratory using blood samples. Results are compared with a reference DNA to identify high-confidence, likely or known pathogenic variants. Predictor snippets re-sequenced. Results are reported to clinicians, patient and family and placed in the EHR. For positive results, EHRs are reviewed to check if an illness has already been identified. Professionals are informed first to familiarise themselves with the results and the implications for care, after which patients are notified and given the opportunity to discuss implications of the result for their health care. Information on first-degree relatives is also communicated in a family letter. Results are also deposited in publicly accessible databases.

A variety of follow-up options with the team of health care professionals is available to patients, depending on whether or not they are insured with Geisinger. The genetic information can lead to a number of follow-up actions in clinical care, such as conducting additional diagnostic tests, recommending additional interventions or closer monitoring of medication adherence or life style. The

effects of using genetic information in care are monitored according to an outcomes framework and using EHR data. The framework contains metrics related to process, health status, costs, behavioural factors and patient-reported measures.

Approximately 3-4% of sequences identify clinically actionable information, about 50% of which is new information, in particular about family members. Evidence of the effects of integrating genetic information in care, whether in terms of process, health outcomes, or cost, is not yet publicly available.

A challenge in integrating genomic information into clinical practice is to choose the variants that should trigger follow-up action. Therefore, only variants with high certainty about predicting disease are reported (currently 76 variants) while information on low-certainty predictors is retained for subsequent analysis. To move towards a learning health system, clinical data are fed back into the sequence to improve variant annotation and the understanding of the effect of genetic variants on the risk of disease. The initiative is also quite resource intensive, requiring a good data infrastructure and analytical capacity to compare sequences to reference DNAs as well as a sufficient number of genetic counsellors to interpret and communicate implications. The interpretation of results is generally more difficult and fuzzy than for diagnostic tests, not least because patients are enrolled regardless of disease status so that the probability of a given patient's having a condition associated with a predictor is low and the risk of false positives is high.

Source: Geisinger, personal communications; Williams et al (2018[18]), "Patient-Centered Precision Health In A Learning Health Care System: Geisinger's Genomic Medicine Experience", http://dx.doi.org/10.1377/hlthaff.2017.1557.

2.3. Enhancing care delivery with digital technology

Providing high quality care to patients with complex needs requires that service delivery across different settings is seamless. Everyone involved in providing care – patients, doctors, pharmacists, nurses, dieticians, other allied health professionals, social care providers and so on need to communicate effectively with each other, have relevant and timely information and coordinate their activities.

Shared information systems that enhance communication and information flow across the continuum of care have been recognised for some time as one of the key prerequisites for integrating activities of distinct health care providers (Suter et al., 2009[19]; Gray Steele et al., 2016[20]). The needs of complex patients can best be supported by systems that allow for person-centred and bi-directional information sharing between patients and providers as well as among individual providers, for example through EHRs, tele-monitoring systems or web-based applications (Gray Steele et al., 2016[20]). If ICT-supported care delivery, and improved coordination, can help attract younger and healthier patients to automated and less costly services, capacity could be freed up to focus for more resource-intensive services on more complex patients, leading to efficiency gains.

Despite the various ways that ICT can improve care delivery, the evidence on the effectiveness of new ICT-enabled ways of delivering care to improve health outcomes of complex patients is still weak and not yet conclusive. Similarly, the evidence on the effects of novel ICT that supports patient-centred and integrated health service delivery on patient outcomes is sparse (Demiris and Kneale, 2015[21]). Recent analyses of integrated care projects that use ICT for people with multi-morbidity in Europe, for example, found little evidence that such models of care delivery are effective (Melchiorre et al., 2018[22]; Barbabella et al., 2017[23]).

Interventions for people with complex needs as well as services that rely on ICT are often customised locally and may have multiple and interacting components so that their success or failure depends as much on their implementation in local work flows as on their design. ICT is an enabler of better delivery of care

and should be seen as an essential part of an intervention, not an intervention in its own right (Gray Steele et al., 2016[20]; Melchiorre et al., 2018[22]). It is therefore difficult to generate, synthesise, interpret and generalise evidence of the ultimate effectiveness of technology in isolation.

Nonetheless, there are many and often relatively small-scale initiatives across OECD countries that demonstrate how ICT can be used effectively to improve care delivery, and some of these show promising initial results. A recent study from Australia (Shaw, Hines and Kielly-Carroll, 2018[24]) concluded that many of the ICT tools for health described below, including patient portals, mobile technologies that deliver information such as patient reminders, electronic discharge summaries and clinical decision aids, can improve patient outcomes. The authors also cautioned, on the other hand, that such tools can also have negative effects on practice, user experience and outcomes if not designed or implemented appropriately (ibid.).

This section aims to answer the question of *how ICT can be used to enhance service delivery*, in particular for patients with complex health needs. While ICT supports the formulation of guidelines and personalisation of care pathways as well as needs-based health service planning and resource allocation (see Chapter 8 on system governance, stewardship and resource allocation), digital technology also allows for the set of services to be delivered to patients more effectively and efficiently, while making them more responsive to needs as patients move through the health system.

A number of avenues show promise in employing ICT for improving outcomes and making care for complex patients more efficient. This section identifies four such avenues: giving patients access to their own data and facilitating patient-provider communication; enhancing communication and coordination among providers; using data to improve decision making in clinical practice; and tele-medicine. This section relies mainly on case studies from OECD countries to show different ways in which ICT can be used effectively in care delivery. Case studies are instructive through illustrating innovative ways in which ICT can be used to tackle challenges identified locally. Rather than prescribing *off-the-shelf* solutions, this can help decision makers learn about experience elsewhere and apply the lessons to their local context.

2.3.1. Giving patients access to their own data and facilitating patient-provider communication

Easily accessible and understandable information on health and health care can empower patients, improve their health behaviours and self-care and enhance support by informal caregivers. At the same time, tools that provide for two-way data exchange can also enhance communication between patients and providers. Better provider-patient communication can improve the responsiveness of health services and, ultimately, improve outcomes and increase patient satisfaction. While having access to data can increase self-management capacity, self-management cannot replace professional care. Rather, it can enable patients not only to improve their own health behaviour but also to reach the health care they need (Morton et al., 2017[25]).

ICT, such as web-based portals and mobile apps that are integrated with information systems of health care providers, can make personalised information available to patients at low cost and encourage information exchange between patients and providers. Tools that make personal health information accessible to patients, by tapping into existing information systems such as but not only electronic medical and health records (EMR and EHRs), are often referred to as *patient portals*. They can increase patient awareness and help them make decisions, giving them more confidence in their care and reducing anxiety, fear and uncertainty (Roberts et al., 2017[26]; Morton et al., 2017[25]). Studies also found that patients appreciated the ability of technology to share information with their families (Roberts et al., 2017[26]).

Patients with complex needs benefit from empowerment through information

For patients with complex needs, patient portals are best integrated with a range of tools that help them manage their health and facilitate patient-provider interactions. Because of the co-occurrence of several health problems and the breadth of services they receive, such patients can benefit particularly from more accessible information about their health and health care. A recent literature review from Australia found that successful patient portals are integrated with provider information systems, such as EHRs, and with clinical decision support tools, and provide functions for secure messaging, patient reminders and prescription refill orders (Shaw, Hines and Kielly-Carroll, 2018[24]).

While enhanced information in itself can support self-management through increasing awareness, patient portals are especially effective for complex patients when integrated with self-management applications. They can also be integrated with remote monitoring tools that feed information systems with patient data while patients are not in contact with their health care providers (see Section 2.3.4). Importantly, all these ICT solutions are more effective when part of broader strategies that make care more patient-centred, such as case management (Goldzweig et al., 2013[27]).

Patients who use self-management applications ('apps') have been found to perceive greater awareness of their condition, to be better able to make health-related decisions and feel more equal to professionals allowing them to engage in meaningful discussions (Morton et al., 2017[25]). Apps that allow patients to learn interactively, especially through self-assessment and feedback features, increase patient participation in their care (Roberts et al., 2017[26]).

Self-monitoring of data can motivate patients to engage in behaviours that help improve their health outcomes, even when using applications that do not support behaviour change explicitly (Morton et al., 2017[25]). For example, perceiving an interaction between certain activities and physiological data, such as reducing blood pressure by adhering to medication, to better manage diabetes through physical activity and diet, or to control COPD by engaging in more physical exercise, not only encourages further self-monitoring but also motivates to engage in self-management in order to see an improvement in the data (ibid.) This motivation to change behaviour based on physiological data was found even among patients using standalone monitoring systems with no explicit support for behaviour change or educational functions (ibid.).

The Swedish ePATH (electronic Patient Activation in Treatment at Home) project applied a user-centred design process to incorporate a number of ways of enhancing the self-care capacity of patients with chronic or complex diseases (Schildmeijer et al., 2018[28]). In addition to informing patients through functions for planning self-care activities, medication management, health and symptom tracking, and two-way communication with health care providers, the application used various psychological tools to motivate patients to engage in self-care. Through recording self-care activities, health care providers could get a better understanding of symptom development and medication adherence (ibid.).

Technologies that help engage patients in their care are underused

The benefits of giving people access to their own data are many. But recent studies suggest that systems that share and actively provide health data to patients to support self-management are still under-used, in particular for complex patients. A recent analysis of integrated care projects that use ICT for people with multi-morbidity in Europe, for example, found that ICT that supports patient self-management is among the tools least used in these projects (Melchiorre et al., 2018[22]). Barbabella et al. (2017[23]) found that nine in ten hospitals in Europe (90%) do not permit patients to access their own health data. Similarly, in programmes to improve care for multi-morbid patients, tools for sharing of information mainly focus on interactions between professionals and provider organisations, not on making information available to patients (Melchiorre et al., 2018[22]).

For the potential of personalised health information to be realised, patients also have to actively access and used the information that is made available. However, people have sometimes been slow in the uptake of tools such as patient portals (see, for example, NHS Digital (2019[29]) and Adler-Milstein and Longhurst (2019[30])). This underlines the need not only for user-centred design of such solutions but also for supporting people in accessing and making use of the information that is made available.

Although their own data are not yet actively provided to patients in many new models of care delivery, many OECD countries are currently investing in patient portals that make enable people to access their health information and increasingly integrate these systems with the wider health information architecture. Of 15 countries who responded to the survey conducted during research for this report, 12 (80%) reported that they already have or are in the process of implementing an ICT system that gives people access to their own health data.

In Australia, for example, the My Health Record system provides a secure online summary of key personal health information and is available to all residents. Per November 2018, approximately 25% of the Australian population (more than 6 million people) were registered in the system and more than 14 000 health care provider organisation were registered to contribute data, including primary care practices, hospitals, pharmacies, diagnostic imaging labs and pathology practices. In 2019, the Australian government moved towards an opt-out principle to improve uptake of the My Health Record system, so that all residents will have a record by default unless they choose not to have one.

In Canada, the provincial government of Nova Scotia offers its residents a patient portal called MyHealthNS. The portal allows patients and doctors to share information, including routine test results. Once patients have created their secure online health record, they can receive and store test results and specialist reports electronically. They can also log health information, such as blood pressure readings, immunisations, allergies and medications.

All Estonian citizens have access to their electronic health record through a national patient portal using their personal identification number and the relevant security measures tied to it. The portal not only provides access to data but also has a number of basic interactive functions (see Box 2.2).

Box 2.2. The Estonian patient portal

In Estonia, all citizens who are insured by the Estonian Health Insurance Fund have access to their health data through a web-based patient portal. The portal provides access to the national health database, which unifies data from various health care providers in electronic health records (EHR). People can view their medical data, including data entered by health care providers on diagnoses, test results and their interpretations, and treatments received as well as data on medicines prescribed and dispensed.

In addition to providing access to data stored in their EHR, the portal allows people to create summary documents (such as case summaries and dental care charts), set up reminders, book appointments, inform all medical institutions simultaneously about changes in their contact details, make declarations of intent (such as registering for organ donation) and initiate administrative processes. For example, instead of seeing a health care provider for such purposes, they can apply for health certificates through virtual medical checks that use existing medical data in their EHR and make such documents available for administrative purposes, for instance for getting a driving license.

By default, all citizens can access their own data and health care providers can access data of their patients. Parents also have access to data of their underage children. However, users are their own access administrators and can restrict data access selectively or opt out of the system entirely at any time. Adult users can authorise other persons to access their data and appoint representatives for the performance of certain activities (for instance for buying prescription medicines) so that, for example,

people can support the care of their parents or grandparents. A function to give consent for use of data for research purposes is currently under development.

For data security, the system relies on digital authentication for access, digital signing of all data, encryption and decentralised data storage, and logging of all activity backed by blockchain technology. People access the portal using their digital identity card tied to a citizen ID, which is identical for all public services, including health care. Every data query results in an unalterable log so that any potential abuse remains fully traceable. Data access logs are monitored centrally and by users themselves, who can check by whom and when data were viewed. In the past, health care providers who accessed data without appropriate authorisation already faced severe disciplinary measures, including loss of their license to practice.

As per 2018, the portal has been actively used by approximately 480 000 people, representing 37% of the Estonian population. Just under 700 people have opted out of the system, which represents less than 1% of users.

Source: Based on Estonian Ministry of Health and Estonian Health Insurance Fund, personal communications; https://www.sm.ee/en/patients-portal-and-health-information-system.

In Finland, the city of Oulu has opened the *Self-Care* platform to all of its citizens since 2010. Self-care is a web-based communication platform for patients and professionals that makes available information to encourage healthier life styles and disease prevention and provides support for managing chronic diseases (Lupiañez-Villanueva, Sachinopoulou and Theben, 2015[31]). It is integrated with people's EHR and provides a wide range of functions, including online booking of appointments and sharing of test results; e-prescriptions; an information portal on treatment of chronic illnesses and health promotion as well as nutrition diaries and weight control tools; an advice service through which people can log inquiries that are answered by health professionals; data governance functions for citizens to authorise data transfers between providers; and a tool for providers to monitor the health status of their patients (ibid.).

While *Self-Care* is available to all people regardless of their health status, it has been recognised as a key ICT enabler of the chronic care model also implemented by the city, and supports the shared use of data, not only among health care but also health and social care providers. As per 2017, there were approximately 60 000 registered users among a total population of about 200 000 in the city (Oulu Healthcare and Social Welfare, 2018[32]). The goal is to scale the system to the entire region with a population of about 400 000.

Widening health disparities must be actively avoided

Many people with multi-morbidity are likely to adopt and use technologies that allow access to their health information (Yamin et al., 2011[33]). But evidence also suggests that there are disparities in the use of patient portals between patients with different socio-economic backgrounds (Shaw, Hines and Kielly-Carroll, 2018[24]; Goldzweig et al., 2013[27]). These reflect the digital divide and lower digital literacy among disadvantaged population groups (ibid.).

It is therefore important that implementations of patient portals and other ICT that facilitates sharing of data with patients not only make the electronic tools available but also support adoption by people who can benefit most from their use. In Estonia, for example, training courses and tutorials on digital tools are made available to patients and professionals with lower digital literacy. Human centricity and patient empowerment is also among the five pillars of the Estonian e-health strategy (2015-2020), which aims to develop the abilities of people to self-manage and self-educate using apps and online solutions.

Another way of encouraging adoption by patient populations that can benefit from enhanced access to their data is making tools available in provider settings and having professionals demonstrate and support

their use (Shaw, Hines and Kielly-Carroll, 2018[24]). In the United States, for example, a mobile device-based patient portal is currently under evaluation that engages patients with multiple chronic conditions during a hospitalisation when one of their diseases deteriorates. This approach is taken because a hospital episode is expected to make the health problem more salient to patients and increase engagement (McAlearney et al., 2016[34]). Using the hospital episode as an entry point, the application then aims to increase patient self-management following discharge through various functions. It provides health summaries, medication listings, daily care plans, health education videos and other materials, advice on prevention, secure messaging with providers and appointment tracking and a patient interface for health data entry. The solution is integrated with EHRs maintained by providers.[5]

2.3.2. Communication and coordination among providers is key to improving care and health outcomes

Coordination of activities between the wide range of different providers involved in care of complex patients is key to improving outcomes and avoiding harmful treatment interaction and waste. By definition, ICT can play an enabling role in improving communication and coordination across all settings and professions involved in the delivery of care, including transitions between hospitals and home- and community-based care and transitions between health and social care.

In a survey in Scotland, for example, GPs reported that they believed that sharing of data through an EHR system enhances patient safety, improves clinical management, reduces hospital admissions, empowers clinicians, aids communication across services and enables decisions to be responsive to patients' wishes (Craig et al., 2015[35]). Doctors also believed that patients with multiple and complex health problems benefit particularly from information sharing (ibid.).

A recent review of care delivery models that use ICT and aim to improve care for elderly people with multi-morbidity found that tools that improve communication and coordination among providers, in particular shared EHRs, are one of the most common ICT components of such models (Melchiorre et al., 2018[22]). Managers of these care models reported that ICT-supported care coordination led to improvements in the quality of care, quality of life of patients and the efficiency of care (ibid.). In another example, adoption of EHRs in hospitals in the United States was found to be associated with reductions in mortality (Lin, Jha and Adler-Milstein, 2018[36]).

Integrated health record systems are an important foundation

Interoperability and shared data standards or integrated information systems play an important foundational role in enabling this communication and coordination among service providers. Many countries are making good progress in implementing a single, integrated EHR system. In Lithuania, for example, the central e-health system (ESPBI IS) stores patient information from various providers in a single and shared repository, following the principle of 'One Resident – One EHR'. The system also provides electronic workflows for appointments, referrals and e-prescriptions that save time and reduce errors in transmitting information, making provider interactions more efficient. At the same time, patients can securely access their data online, through a patient portal (a similar patient portal that provides access to EHR data in Estonia is described in Section 2.3.1). Nearly 95% of the Lithuanian population have an EHR and, by mid-2018, more than 70% of providers were connected to the central e-health system.

In the NHS Scotland projects are underway to make electronic records interoperable between the health and social care system, which have historically relied on separate record systems (Gray Steele et al., 2016[20]). This is particularly important for patients with complex needs, who often require health and social care. Time will tell if initiatives such as the ones described here result in better care outcomes and efficiency. Evaluation of initiatives such as these, while challenging, is very important (see Section 2.4.3).

Of course, enabling a range of providers' access to personal health data introduces risks. Authorisation of access and any alterations to the information must be tracked. This can be enabled by ancillary digital technologies such as a blockchain, which does not hold any health or clinical data but can provide a record of authorisation and access to the data. Estonia, for example, tracks all changes to information on EHRs – including when, where and by whom the entry was made – and keeps a record of all amendments in separate places including on a blockchain. This provides an immutable log should an unauthorised access and manipulation of data occur.

Other ICT functionalities can also contribute

While a shared and interoperable EHR system is a linchpin of care coordination, a wide range of data-driven modalities are available to share information effectively and ultimately improve the people-centeredness and integration of care. A recent review by the RAND Corporation identified five key ICT functionalities that are widely used already or being piloted for care coordination: dashboards, patient relationship management, event alerts, referral tracking and care plans (Rudin et al., 2017[37]). These functions are most effective when integrated with each other and with existing information systems.

Shared electronic care plans, for example, can provide personalised care pathways defined by patient need and outline optimal treatments to both providers and patients. In addition to including shared patient background information, they can include care team member designations that help professionals understand their responsibilities, and task management functionalities that improve treatment adherence (Rotenstein et al., 2016[38]). Similarly, electronic hospital discharge summaries (EDS) can be simple and effective tools to improve coordination of care between hospitals and community-based providers. EDS can be populated and sent automatically from hospital EMR systems and be integrated with reminders for health professionals responsible for post-discharge care.

ICT that allows for remote delivery of services (see Section 2.3.4) can also support interactions among professionals, saving time and making care more efficient. Various ICT-based solutions have been implemented in OECD countries to improve information exchange between professionals to bring medical expertise closer to patients rather than moving patients physically to where expertise is located, especially by linking local providers with specialists based far away.

In Estonia, for example, an e-consultation service has been implemented that allows GPs to consult with specialists on difficult cases online. GPs then either implement specialist advice themselves or refer patients to further services that are necessary. Uptake of the service is incentivised by the Estonian Health Insurance Fund, which pays specialists the same rate for e-consultations as for face-to-face patient contacts. In England, some NHS Clinical Commissioning Groups have implemented virtual services for GPs to send questions to specialists for a quick reply, eliminating the need for specialist appointments. Such services enhance the role of GPs in providing care and frees up specialist time, through avoiding unnecessary referrals. Similar remote consultation services are available to primary care professionals in Canada.

In Poland, a "telestroke" system is being established to increase the speed and therefore effectiveness of treating stroke. The telestroke system uses ICT for remote consultations between specialised stroke centres and local providers where specialists are not available. Project ECHO is an initiative based in the United States developing ICT-based services to support community-based health professionals with remote specialist advice covering a wide range of medical specialties.[6] It also allows specialists to learn from cases located far away.

Challenges to deploy ICT relate to engagement and workflow redesign

However, significant barriers remain to greater use of ICT for care coordination. These include, for example, limited engagement of professionals in development and implementation of tools, and attendant

challenges with their integration into existing workflows, slow adoption and sub-optimal use, and a lack of standard definitions of the purposes and functions of tools as well as the roles of users (Rudin et al., 2016[39]). Greater user involvement in designing tools is one way to reduce barriers to their adoption (see Section 2.4).

As such, ICT tools that encourage better coordination and integration of care for complex patients are not yet ubiquitous across health systems of OECD countries. Of the 15 countries that responded to the survey conducted in the research for this report, 9 (60%) mentioned initiatives to allow for and/or promote electronic exchange of data between providers. Four countries (27%) reported that patients with multi-morbidity or other types of complexity have been identified as a specific target group for new ways of care delivery and only 2 countries (13%) reported that they are implementing integrated care for such patients. The latter does not necessarily mean that such care delivery models do not exist – but they may not have gone beyond local pilot initiatives yet and may not be a system-level priority.

However, in many OECD countries there are examples of integrated care delivery models that are supported by ICT and the use of data. Many Spanish regions actively enrol complex patients into integrated care. An example of such a model from the Basque Country is in Box 2.3.

In Australia, the Health Care Home (HCH), currently being trialled, aims to provide coordinated and team-based care for patients with chronic and complex conditions, supported by ICT. All patients enrolled in the HCH have an electronic care plan, defined and overseen by a nominated clinician who takes overall responsibility for the care of an individual patient. This electronic plan is shared with patients and all professionals involved in their care. The shared care plan aims not only to increase coordination of the services but also patients' own participation in their care, both inside and outside of the HCH. Providers are also expected to share patient data and use such data to monitor and track patient health indicators and outcomes (Health Policy Analysis, 2017[40]). A 2-year evaluation of the effects of HCH in terms of quality of care and patient experience, provider experience, health service use and costs is due to be completed by the end of 2019 (ibid.).

Box 2.3. Integrated care in the Basque Country (Spain)

The Department of Health of the Basque Government has implemented integrated care for frail elderly adults and patients with multi-morbidity. This is part of an overall 'Chronicity Strategy' adopted in 2010, which includes risk stratification of the entire Basque population, and is supported by a broad e-health Strategy. Based on the stratification, the Basque health authority provides population-level prevention, disease management, or integrated case management for the most complex patients with multi-morbidity. Integrated care aims to improve continuity of care, adherence to therapy and, ultimately, patient experience and health outcomes. By October 2017, more than 4 000 patients were enrolled in integrated care. The target for 2019 is to enrol 16 000 patients.

At the core of the care delivery process are "Integrated Care Organisations" (ICO) that oversee primary and hospital care for a defined population catchment area and provide preventive interventions and personalised care. Care relies on three provider pillars: hospital-based professionals overseen by reference internists; primary care teams; and a 24/7 nurse-led call centre. New roles have been defined for nurses who act as liaison officers and case managers. The model aims to improve the management of polypharmacy, patient empowerment and self-management capacity and coordinate health and social care.

An e-health Strategy and various ICT tools support care delivery. These include a patient portal, a shared electronic health record (EHR), an electronic prescription system and tele-monitoring. A custom version of the Adjusted Clinical Groups Predictive Model (ACG-PM) is used for risk stratification and case finding, unifying various data sources (e.g. including demographics, ambulatory and hospital

diagnoses, prescriptions and service utilisation). Risk stratification is not only used to identify the right patients to enrol into integrated care but also to support the formulation of needs-based care plans. The same data are also used to feed business intelligence (BI) software that generates scorecards for managers to monitor care delivery.

Monitoring is based on a range of process- and outcome-related indicators, defined across nine domains including effectiveness, efficiency and equity. Indicators include, for example, rates of hospital admissions, readmissions and mortality (to gauge effectiveness); costs of primary care consultations, emergency room visits and hospitalisations (to gauge efficiency); and breakdown of the patient population enrolled by sex and income (to gauge equity).

Results of rigorous studies that evaluate the effectiveness of the integrated care model are not yet available. Evaluation of the pilot project (2015-16) found improved care coordination, lower numbers of hospital admissions and visits to the emergency room, higher numbers of GP consultations and increased patient, family and caregiver satisfaction. Before-and-after comparisons found a 12% reduction in hospital days for multi-morbid patients and decrease in readmission rates of nearly 17%. The model has been deemed cost-effective overall, mainly by improving outcomes while remaining cost-neutral.

Source: Based on Basque Regional Health Authority, personal communications; Scirocco Project (2017[41]), "Overview of Scirocco Good Practices: Basque Country - Care Plan for Elderly", https://www.scirocco-project.eu/wp-content/uploads/2017/04/SciroccoGP-Basque-6-Care-Plan-for-Elderly.pdf.

Implementing ICT must be part of a broader change and improvement strategy

To truly achieve patient-centred and integrated delivery of health care, however, adoption of ICT that can enhance communication and coordination of care needs to be part of a much broader effort to establish teamwork and collaboration among professionals as a the standard way of operating. This requires not only the right policy framework that encourages cooperation and greater care integration, through institutional structures and incentives, but perhaps nothing short of a fundamental cultural change in the way health professionals are educated and work (Mulvale, Embrett and Razavi, 2016[42]). The workforce considerations of implementing ICT are explored in more detail in Chapter 4.

Examples of projects in OECD countries that aim to improve communication and coordination between providers show that ICT, data and better information can be a key enabler of better collaboration between providers. But instituting the necessary *behavioural* changes and ensuring that ICT and knowledge are used effectively remains the biggest challenge.

To make care delivery more person-centred and improve the management of chronic disease and multi-morbidity, the Veneto region of Italy introduced Integrated Medical Groups (IMGs) in 2016 as a new model of delivering primary care (Ghiotto et al., 2018[43]). These groups comprise at least 4 general practitioners as well as nurses and other health professionals are embedded in local health units, which promote the integration of health and social care and between hospitals and other medical services, share electronic medical records and provide care in accordance with pre-defined diagnostic-therapeutic pathways (ibid.). These pathways define the respective roles and responsibilities of professionals and how they cooperate among each other; they also aim to promote patient engagement. The extent to which professionals enter and share structured information is monitored.

Germany has historically relied on professional autonomy and office-based physicians in solo-practice as a predominant way of providing outpatient care. Statutory health insurance provides patients with free choice of GPs and specialists and access to care without cost at the point of service. These characteristics pose a challenge in care for chronic diseases. The Joint Federal Committee (G-BA) currently funds the Accountable Care (ACD) project, which uses routine data from sickness funds to identify patients with

chronic diseases who see multiple office-based physicians and then aims to improve care coordination among them through moderated working groups (see Box 2.4).

Box 2.4. Accountable Care (ACD) in Germany

The Accountable Care (ACD) project was launched in 2017 with the goal of improving cooperation and regular feedback among office-based physicians to improve the quality of health care by reducing avoidable hospitalisations and improving patient outcomes. Improving job satisfaction of physicians was another goal. It targets patients with one or more of 14 diseases with a high proportion of avoidable hospitalisations. Most diseases are chronic, including hypertension, diabetes, COPD or chronic back pain.

The absence of formal gatekeeping by general practitioners, no shared electronic health record, free provider choice by patients and the attendant lack of coordination among providers, in particular office-based physicians who often work in solo-practice, have been identified as challenges in care for chronic diseases. Estimates suggest that 60% to 90% of hospitalisations for chronic diseases could be avoidable. The German Joint Federal Committee (G-BA) funds this 3-year project using routine data to improve cooperation among office-based physicians.

Pseudonymous routine data from four German regions are analysed to identify patients who are seen by several office-based physicians (referred to as “shared patients”) and corresponding de-facto physician networks. Physician networks receive information on their existing networks, including typical patient pathways, and are asked to improve cooperation by defining communication channels, action plans and care pathways. Providing physicians with this information on how they are connected with their colleagues and on the outcomes of care delivered within their informal networks can help them make improvements and strengthen their awareness of possible discontinuities in care. Trained moderators lead “quality circle” meetings every six months to provide structured dialogue. Patient outcomes and medical guideline adherence is monitored and fed back to physician networks quarterly. Patient-reported indicators are aggregated and reported at the network-level. In addition, all participating physician practices receive analyses of routine data pertaining to all other patients they treat.

Following an application to the relevant regulatory authorities in accordance with the German Code of Social Law, data from the associations of statutory health insurance physicians and data from sickness funds were linked within a Trust Centre at LMU Munich. These data encompass all patient contacts with the ambulatory care sector and hospitals stays that are billed to the sickness funds, including information on diagnoses, procedures and prescribed medication. Linking the routine data from the sickness funds with the data from physician associations allows for visualising actual patient care pathways.

However, some information on cross-sectoral services and services purchased through selective contracting are not available in the dataset. The linking of routine data with more comprehensive and meaningful data on clinical parameters could further improve the quality of feedback to physicians. Another barrier to more effective and efficient sharing of data is a lag of 10 month in data availability.

The care delivery model is currently evaluated in a cluster-randomised controlled trial (cRCT), with some physician networks engaging in the quality circles and performance monitoring and some assigned to a control group. Evaluation is due to be completed in 2020. The 3-year project led by Ludwig Maximilian University (LMU) Munich received EUR 3.8 million in funding from the G-BA Innovation Fund.

Source: Based on German Joint Federal Committee (G-BA) (2019[44]), “ACD – Accountable Care in Deutschland - Verbesserung der Patientenversorgung durch Vernetzung von Leistungserbringern und informierten Dialog”, https://innovationsfonds.g-ba.de/projekte/versorgungsforschung/acd-accountable-care-in-deutschland-verbesserung-der-patientenversorgung-durch-vernetzung-von-leistungserbringern-und-informierten-dialog.45.

2.3.3. Data-driven decision aids in clinical practice enhance diagnosis accuracy and appropriateness of treatment

Computers far exceed the abilities of the human brain to process large amounts of data. Clinical decision-support systems can match the characteristics of individual patients to large volumes of data and use algorithms to create personalised predictions of disease status, diagnoses, appropriate treatment and help make other clinical decisions (Shaw, Hines and Kielly-Carroll, 2018[24]). Decision aids can thus improve the accuracy of diagnosis and treatment decisions made by professionals.

Decision aids can be used in variety of health care settings. For example, algorithms have now been used successfully for some time in interpreting diagnostic images and have been shown to outperform humans in certain tasks related to diagnoses and prognoses (Litjens et al., 2017[45]; Dimitriou et al., 2018[46]; Topol, 2019[14]). Algorithms can also be faster than humans in interpreting diagnostic images, which can have positive effects on treatment outcomes if delays in making decisions puts patients at risk (Arbabshirani et al., 2018[47]; Topol, 2019[14]). In the emergency room, computerised clinical decision support systems have been found to improve care in terms of process-related measures (Bennett and Hardike (2016[48]), also see Chapter 4 on the health workforce).

Only 2 of 15 countries that responded to the survey conducted in research for this report reported projects to implement clinical decision support systems. There are, however, some examples of innovative care delivery models that feature digital decision support systems. The Finnish POTKU model, for example, provides GPs with the locally-developed *Evidence-Based Medicine electronic Decision Support* (EBMeDS) system. The system matches evidence-based treatment guidelines and recommendations with patient records and provides personalised care guidance (Hujala et al., 2016[49]). The system also generates automated reminders and warnings (ibid.).

Decision support can be especially useful in complex patients

Patients with complex needs can benefit particularly from decision support algorithms because they often need treatments for several diseases at the same time, which creates complex combinations and risks of adverse interactions. Polypharmacy is often the consequence of having several chronic diseases so that polypharmacy is highly prevalent among older population groups and people with complex health needs. For example, in Sweden a population-based study found that, in 2010, an average adult aged 65 years or above was exposed to 4.6 medicines at the same time (Morin et al., 2018[50]). In this elderly population group, 44% of people were exposed to five or more drugs at the same time, and 12% to ten drugs or more (ibid.)

As described in Section 2.2, treatment guidelines can be contradictory for patients with multi-morbidity because medical research continues to focus on single diseases. Algorithms that match all diagnoses and characteristics of a patient to recommended treatments can help identify possible adverse treatment interactions if clinical guidelines conflict and provide mitigation strategies. To manage complex drug interactions in patients with polypharmacy, algorithms can use electronic data on prescriptions to generate automated warnings of high-risk drug combinations or drug-induced complications to prescribing physicians, pharmacists and patients (Molokhia and Majeed, 2017[51]). Sharing of electronic prescription data can avoid prescribing errors that happen simply because prescribers are not aware of all the drugs taken by their patients (Lavan, Gallagher and O'Mahony, 2016[52]).

Electronic drug monitoring tools can also make health care more efficient by freeing up time spent by professionals on tasks that can be automated, without compromising outcomes. A study of the work of nurses in an Australian hospitals, for example, found that nurses spent significantly less time on medication monitoring tasks and more on other patient care-related tasks following the implementation of an electronic monitoring tool for rheumatology patients (Callen et al., 2013[53]).

Ensuring patient involvement in decision making

Patient involvement in decision-making is an important part of patient-centred care. Algorithms can also be designed to take into account patient preferences (Wilk et al., 2017[54]; Zamborlini et al., 2016[55]). However, patient involvement is still the exception rather than the rule. A literature review published in 2015 found that patient participation in making decisions is still limited and that few tools are developed to actively and directly involve patients in the decision process (Sacchi et al., 2015[56]). Similarly, a review that focused on decision aids in the care for patients with multi-morbidity also found that patients were often not actively involved in the decision-making processes (Fraccaro et al., 2015[57]).

Integration and interoperability are of vital importance

Interoperability of information systems and data quality are key to realising the full potential of data-based decision aids. Algorithms can only produce accurate and personalised care recommendations if underlying data are accurate and contain the necessary variables to provide complete personal profiles of patients. This requires combining personal data from disparate sources. However, many decision aids currently used do not yet take a *system medicine* approach to integrate data from various sources. For example, Gietzelt et al. (2016[12]) found that many decision models only use a single type or source of data and few combine more than two types or sources of data. Decision models that do combine at least two types of data most commonly use genomics and molecular data combined with clinical data extracted from electronic medical records (ibid.).

Data from EHRs are also used for predictive modelling to improve the appropriateness of care as patients receive treatment. For example, EHRs have been used at Kaiser Permanente in the United States to predict deterioration of hospital inpatients and unplanned transfer to intensive care units (Kipnis et al., 2016[58]). In another study using EHR data from Canadian and United States university hospitals, deep learning algorithms achieved high accuracy in predicting disease onset, hospital mortality, unplanned readmissions, prolonged length of stay and the final discharge diagnoses of patients (Rajkomar et al., 2018[59]; Miotto et al., 2016[60]).

Decision support systems are best integrated with other ICT tools that support the delivery of care and embedded into clinical workflows. In the United States, emergency room software that unifies all relevant patient information and integrates it with checklists and decision-support was found to reduce mortality and length of stay, resulting in cost savings (Olchanski et al., 2017[61]). A recent review from Australia found that decision-support systems are most successful when implemented in combination with additional software components and that their adoption, and ultimate effect on the quality of care, can be improved by ensuring interoperability with existing ICT systems and focus on a local minimum set of indicators (Shaw, Hines and Kielly-Carroll, 2018[24]). Integration with other ICT systems is also key to understand the entire range of information various systems deliver to health professionals and patients, to help ensure that people are not overloaded with information and risk ignoring the most important alerts that decision support systems deliver.

More research is needed to establish the effectiveness of decision aids

Although the utility of decision aids may be more straightforward to evaluate than other ICT tools (through independent validation of the appropriateness of recommendations the systems generate) evidence of decision aids' effectiveness remains patchy. A review by Bennett and Hardiker (2016[48]) concluded that there was mainly low-quality evidence of the effectiveness of decision aids used in emergency care. Looking at decision aids in the care for patients with multi-morbidity, a review by Fraccaro et al. (2015[57]) found that there were no rigorous evaluations of usability or effectiveness of the tools used.

2.3.4. Tele-medicine can make care more appropriate and efficient

One of the most common applications of ICT in the health sector is tele-medicine, which can be defined as the use of ICT to deliver health care at a distance (Cravo Oliveira Hashiguchi, forthcoming[62]).[7] The scope of tele-medicine is broad. It includes tele-monitoring, whereby health care professionals can monitor vital data of patients as well as disease symptoms, signs and signals remotely through the use of ICT, and interactive tele-medicine, whereby ICT is used to bridge geographical distance between patients and providers to for patient/provider interaction and for remote delivery of medical services, such as tele-consultations (ibid.).

In Israel, for example, the national digital health program launched by the government in 2015 includes various initiatives related to remote patient monitoring and remote service delivery. The Ministry of Health has established a tele-medicine platform that can be used by all health care providers in the country for the provision of remote services to patients and to enhance information exchange between providers (See Box 2.5). The four statutory health insurance funds that operate their own provider networks and also function as health maintenance organisations (HMOs) provide tele-consultation services with general practitioners, paediatricians and dermatologists. One HMO offers an interdisciplinary remote consultation service to provide online support and treatment for patients with chronic diseases.

Box 2.5. The national tele-medicine platform in Israel

As part of the national digital health plan launched in 2015, the Israeli Ministry of Health funded and developed a national tele-medicine platform, which provides tele-monitoring functions, allows for remote service delivery to patients as well as improved communication among providers.

The platform aims to make services more accessible for patients with limited mobility and those living in peripheral areas that are poorly served by existing provider infrastructure and to reduce the reliance on private providers by broadening availability of public services. It also allows for urgent after-hour consultations. Providers that use the tele-medicine platform have full access to patients' medical files and can share information with other providers electronically. Four distinct services based on the platform are currently being piloted.

Chronic Disease Management provides in-home monitoring devices to patients with chronic disease. The monitoring system is connected to a central medical call centre that can dispatch appropriate services based on the data received. The service aims to improve adherence to treatment plans, reducing unplanned hospitalisations and other avoidable service use.

Health Data Management automatically manages and analyses patient-generated health data, such as vital signs and medical history. This solution provides proactive alerts to providers when a patient's condition deteriorates.

Tele-Consultation provides patients the possibility to consult with specialists remotely. The service aims to bridge geographic distance between patients and the specialist services required by their condition through teleconferencing technology. The solution is designed for sessions between a patient and a single physician and between a patient and several physicians. It aims to decrease waiting times, which can have positive effects on health outcomes through earlier disease detection and subsequent interventions, and decrease costs through avoiding face-to-face consultations.

Tele-Rehabilitation provides post-acute rehabilitation services remotely, allowing patients who cannot access such services physically to benefit from rehabilitation support. The service aims to improve quality of care for patients.

Source: Based on OECD survey and personal communications with the Israeli Ministry of Health.

Tele-medicine has a range of advantages and can make care more appropriate and efficient. However, it needs to be deployed carefully for these potentials to be realised. Similarly to other uses of ICT, tele-medicine is a mere tool for facilitating interactions among providers and patients; it is not a medical intervention in its own right. Just like face-to-face consultations, services delivered via tele-medicine can be appropriate for patient needs or inappropriate. If used inappropriately, tele-medicine can exacerbate inequity through favouring access to services by younger and healthier people, create frivolous demand and overburden health care providers by unrealistic expectations of continuous monitoring. Electronic transmission of patient data can also represent risks to privacy.

This section discusses important aspects of tele-monitoring and remote delivery of services. A more comprehensive review of current uses of tele-medicine in OECD countries, evidence on its effect on health system performance and lessons for its appropriate use are available in Cravo Oliveira Hashiguchi (forthcoming[62]).

Tele-monitoring can make care more responsive and appropriate, leading to increased effectiveness and efficiency

Tele-monitoring can increase the awareness of patients' conditions by health professionals and enable earlier and more accurate identification of clinically relevant symptoms, signs and signals through electronic transmission of patient data – in most cases passively (without the patient having to manually input data). This can make health care more responsive and appropriate, improve therapy and medication adherence, avoiding costly interventions later on. Providing professionals with real-time data on their patients may help make face-to-face interactions more timely and focused, and increase patient adherence to treatments, ultimately making treatments more effective (Morton et al., 2017[25]; Noah et al., 2018[63]). By focusing the time of professionals on the most important tasks, tele-monitoring can also increase productivity (Noah et al., 2018[63]).

All of this can particularly benefit patients with chronic diseases, who need treatments over prolonged periods of time and specific acute-care interventions when their conditions deteriorate, and people who live in remote and underserved areas. At the same time, the abundance of data generated by tele-monitoring tools can pose privacy risks, may cause information overload and may lead to unrealistic expectations of patients vis-à-vis health professionals.

A trial in psychiatric care in the United Kingdom, for example, found that providing regular feedback to therapists on patient outcomes allowed therapists to focus their attention on patients who were not on track and to identify and resolve obstacles to clinical improvement, which ultimately alleviated depression and anxiety (Delgadillo et al., 2018[64]). *Outcome feedback* in this context refers to routine monitoring of the patient's condition and comparing the patient's symptoms with those observed in similar cases (Delgadillo et al., 2018[64]; Glazebrook and Davies, 2018[65]).

While many individual examples of the use of tele-monitoring exist in OECD countries, few countries use them on a large scale to improve care. Of the 15 countries that responded to the survey conducted in research for this report, only 4 countries (Canada, Israel, Norway and Poland) mentioned projects to implement patient tele-monitoring systems. Analysis of the WHO Third Global Survey on eHealth (conducted in 2015) found that only Canada, Japan and Spain already had well established and relatively large-scale tele-monitoring systems (Cravo Oliveira Hashiguchi, forthcoming[62]). In Canada, for example, tele-monitoring has been promoted as a tool for patients with complex chronic diseases to improve self-management of their illnesses. *Canada Health Infoway*, the national funding entity that promotes health-related ICT, has made tele-monitoring a priority and funded a number of projects across provinces, including the Ontario Telehomecare project (see Box 2.6). In many other countries, tele-monitoring is often only used in small-scale pilot projects (Cravo Oliveira Hashiguchi, forthcoming[62]).

Box 2.6. Telehomecare in Ontario, Canada

The Ontario Telehomecare project provides coordinated support from primary care to people with complex chronic diseases in their own homes. Goals are to maintain people's independence in their own community, providing them access to appropriate care when needed and decrease the need for emergency department visits and acute hospital admissions, thereby saving costs.

Since 2013, over 9 000 patients have been enrolled in the program. The initial focus was on people with congestive heart failure (CHF) and/or chronic obstructive pulmonary disease (COPD). The program was subsequently expanded to people with diabetes as comorbidity, patients living in supported living environments, patients transitioning from hospital to home and patients requiring remote monitoring, in a shared post-acute care model.

Nurses remotely monitor the health status of patients and provide assistance and coaching for self-care. Patients are provided with a touchscreen device to transmit data as well as a blood pressure cuff, pulse oximeter and weight scale. They also receive training in use of the devices. Patients submit data daily during weekdays to nurses, who review results and contact patients if changes in health status need further investigation. Nurses also get in touch with patients weekly by phone to help develop skills and confidence needed to manage symptoms, medications and lifestyle changes. Physicians can receive regular progress reports about their patients enrolled in telehomecare.

Evaluations of the project found that patients with CHF and/or COPD reported increased confidence in self-managing symptoms, leading to reduction in hospital emergency department visits and hospital admissions. Patients enrolled in the program were also found to have reduced levels of blood pressure while evidence of effects in terms of other health outcomes is not available. However, these studies did not compare the people enrolled in against a control group.

A qualitative study, based on semi-structured interviews, document review, and observation of 39 patients and their informal caregivers and 23 professionals involved in telehomecare, identified a number of facilitators and barriers of implementation. Facilitators included user-friendly technology; patient motivation to participate and increase self-care capacity; the integration of the telehomecare into broader health service provision; and comprehensive program evaluation. The main barriers included issues related to using the technology, such as poor memory as to when to take readings or physical difficulties in using technology for people with functional limitations; time constraints for professionals limitations, gaps in provision of care needed by patients; and barriers to patient participation related to geography and social location.

Source*:* Based on Canada Health Infoway (2016[66]), "Ontario Telemedicine Network Telehomecare Deployment Project: Phase 2-Remote Patient Monitoring", https://www.infoway-inforoute.ca/en/plan/3176-ontario-telemedicine-network-telehomecare-deployment-project-phase-2-remote-patient-monitoring/download; Hunting et al. (2015[67]), "A multi-level qualitative analysis of Telehomecare in Ontario: challenges and opportunities", http://dx.doi.org/10.1186/s12913-015-1196-2; Ontario College of Family Physicians (2016[68]), "Telehomecare supports chronic disease management", https://ocfp.on.ca/communications/telehomecare-supports-chronic-disease-management; Sahakyan et al. (2018[69]), "Changes in blood pressure among patients in the Ontario Telehomecare programme: An observational longitudinal cohort study", http://dx.doi.org/10.1177/1357633X17706286; Stanimirovic et al. (2018[70]), "Impact of telehomecare on health system utilization in patients with heart failure", http://dx.doi.org/10.1016/j.cjca.2018.07.143.

For complex patients, tele-monitoring can be integrated with ICT tools that support patient-self management. Giving patients access to their own data has a number of advantages in itself and the data captured by tele-monitoring tools can also drive personalised supports for self-management, such as reminders, goal-setting or personalised life style advice (see Section 2.3.1). Tele-monitoring tools are powerful tools to improve medication adherence, by enhancing, for example, patient education and patient awareness of their own medication-taking patterns (Vrijens, Urquhart and White, 2014[71]). A randomised pilot study of a tele-medication monitoring system in the United States, for example, showed that such a

system can reduce the number of hospitalisations and length of inpatient stays of patients with chronic heart failure (Hale et al., 2016[72]).

Potential risks of tele-monitoring must be recognised and managed

There are a number of pitfalls to avoid when implementing patient tele-monitoring tools. Most importantly, people need to be comfortable with sharing their data with professionals through ICT tools. A poll in the United Kingdom found that 57% of respondents were willing to share data with the National Health Service via a lifestyle app or fitness tracker (Castle-Clarke, 2018[73]). Adoption of tele-monitoring tools may be more difficult to achieve among elderly patients, who are more likely to have complex health needs. Results from the poll in the United Kingdom indicated a clear generational gradient of respondents: while approximately 70% of 15-24 year olds were "very or fairly willing" to share such data and only 25% in that age group were "very or fairly unwilling" to do so, just under half of over 65 year-olds were willing to share data with the other half unwilling to do so (ibid.).

To build trust and acceptance of tele-monitoring, ensuring data privacy is paramount. While data privacy and security are broader concerns related to all technologies that transmit personal health data electronically, not all technologies currently available are secure. Especially applications that can be downloaded by patients themselves and are not subject to regulatory oversight may bear risks. A review by Dehling et al. (2015[74]) of more than 24 000 mobile health apps available for Apple iOS and Android, for example, found that more than 90% of apps available posed at least some risk of damage through information security and privacy infringements while some 12% of apps were classified in the highest risk category.

Professionals can be burdened by unrealistic expectations of continuous monitoring (Morton et al., 2017[25]). While the feeling of being monitored, in particular when patients are contacted by professionals when the monitored parameters are out of range, can reduce anxiety by patients, it can also induce feelings of over-reliance on professionals. Where the level of patient autonomy permits, one solution to these problems is to make patients responsible for contacting professionals when their data were not within an expected range, which can improve both, patient empowerment and the quality of care by making interactions more effective. The style of feedback has an important influence on how much responsibility the patient adopts for self-management (ibid.).

There may also be emotional barriers to adoption of remote- and self-monitoring tools. A 2015 study from the United States, for example, investigated the perceptions of electronic health monitoring tools by multi-morbid patients (Ancker et al., 2015[75]). It found that patients sometimes perceived monitoring data as an additional burden, that making data more salient to patients can provoke strong emotional reactions and that patients often notice that physicians have more trust in data that is measured by technology than in self-reported information (ibid.).

Evidence is encouraging but difficult to generalise

As with other ICT solutions that have the potential to improve care, rigorous evidence of the effectiveness of tele-monitoring in terms of health care process measures and health outcomes is only just emerging. Because tele-monitoring can be used in many different ways, studies are often context-specific and their findings cannot be generalised easily. Also, studies of effectiveness in terms of health outcomes often only look at patients with specific diseases, and not necessarily the most complex patients with multiple health problems.

A recent OECD working paper found that tele-monitoring improves patient satisfaction, empowerment and reassurance by providing a greater sense of security while away from health care providers. Tele-monitoring has also been found to reduce emergency room visits and unplanned and avoidable admissions to hospitals by following patients more closely in their own homes while it appears to either have no effect

or increase the use of face-to-face primary care (Cravo Oliveira Hashiguchi, forthcoming[62]). Increased use of face-to-face care, whether appropriate or not, is often a result of greater patient awareness of medical needs (ibid.). Where this leads to more appropriate care, tele-monitoring can also improve health outcomes. It has been shown, for instance, to reduce mortality of patients with heart failure (HF). A recent literature review by Noah et al (2018[63]) found that remote monitoring tools had positive early effects in terms of clinical outcomes in the management of some chronic diseases, including COPD, Parkinson's, hypertension and lower back pain. On the other hand, integrated self-management tools were not always effective. The review focused on non-invasive, wearable devices that automatically transmit data to a web portal or mobile application for the purposes of self-monitoring or monitoring by a health professional.

Remote delivery of services can improve access and make care more efficient

Delivery of services across geographic distances using ICT can save time for health care providers and patients and improve access to services in remote areas and for isolated sub-populations. Remote service delivery can thus make health care more efficient and more equitable. However, equitable access to enabling technologies and special support for people with lower digital and health literary are prerequisites for achieving the goal of equity. Policy also needs to ensure that the ease of accessing remote services does not lead to additional demand by population groups with better digital literacy, who also tend to be younger and healthier, at the expense of those in need.

Similar to tele-monitoring, the growing evidence base on remote service delivery needs to be interpreted carefully as ICT can facilitate the delivery of appropriate and inappropriate services alike. Evidence suggests that services delivered remotely result in health outcomes that are comparable to outcomes of care delivered face-to-face, while there are a number of non-clinical benefits to patients, in particular ease of access but also increased timeliness, coordination and continuity of care and promotion of knowledge sharing and continuous learning among professionals and patients (Cravo Oliveira Hashiguchi, forthcoming[62]).

Tele-medicine often complements, rather than replaces, face-to-face care

While remote delivery of services cannot always replace face-to-face consultations, remote interactions with professionals can nevertheless serve as an efficient entry-level contact with the health system, and improve the patient-centeredness, appropriateness and ultimately the effectiveness of subsequent face-to-face services (Pecina and North, 2016[76]). For people with multiple chronic diseases who require care over prolonged periods of time, remote delivery of care can greatly enhance access to appropriate services, in particular for people with limited ability and those living in areas that are remote or have poor provider infrastructure. Remote service delivery is best integrated with remote monitoring solutions described above.

In Australia, for example, Head to Health is a digital mental health gateway that aims to improve access to mental health services most suited to peoples' needs through a stepped-care approach supported by ICT. Services can be accessed through a single webpage,[8] which either makes electronic services available directly, allows people to access remote telephone and online crisis counselling and to schedule face-to-face consultations with professionals. Digital services generally focus on highly prevalent conditions, such as anxiety and depression, and are delivered via desktop computers and mobile apps.

For people with multiple chronic diseases who require care over prolonged periods of time, remote delivery of care can greatly enhance access to appropriate services, in particular for people with limited mobility and those who live in areas that are geographically remote or have poor provider infrastructure. This requires that remote monitoring solutions described above are integrated with remote service delivery and that information generated by remote monitoring leads to appropriate patient/provider interactions. The review by Melchiorre et al. (2018[22]), however, found that electronic tools for remote monitoring and patient/provider interactions are not yet widely used in care delivery for patients with multi-morbidity. Impacts on costs and efficiency need to be monitored and evaluated carefully.

The effects of remote service delivery on total costs and efficiency are not easy to predict. Where remote consultations replace and avoid unnecessary, face-to-face contacts and help avoid unnecessary face-to-face consultations, they can lead to cost savings or efficiency gains. By providing an easy first point of contact with the health system and making services more accessible, however, they can also increase demand for both, remote and face-to-face provider consultations and increase costs (Castle-Clarke, 2018[73]). Evidence on cost-effectiveness of care delivered through tele-medicine is context-specific and cannot be easily generalised with the data that are reported (Cravo Oliveira Hashiguchi, forthcoming[62]). As illustrated in the example of the UK Personalised Integrated Care Programme (Section 2.2.1), additional demand may also represent previously undiscovered health need, leading to better outcomes (and perhaps reduced long-term costs).

In another example, an initial evaluation of the "GP at Hand" primary care practice in London found that patient registration with the service coincided with declines in the use of emergency services, suggesting that there may be some efficiency gains from replacing costly hospital services. At the same time, the rapid uptake of services by people who are relatively young and healthy suggests issues with financial sustainability if the care delivery model were to be scaled. The initial evaluation of GP at Hand also indicated that people preferred remote consultations with physicians over automated services (Ipsos MORI et al., 2019[77]), suggesting that efficiency gains by substituting human resources may be difficult to achieve. Further information on GP at Hand is in Box 2.7.

Box 2.7. Babylon Health "GP at Hand" in London, England

GP at Hand is a primary care practice in central London that that provides remote consultations as first point of contact between patients and primary care professionals since July 2017. The practice is privately owned by Babylon Health and funded by the National Health Service (NHS) through the local Clinical Commissioning Group (CCG).

The CCG had a patient population of 231 000 people as per 1 January 2018. The number of people registering with GP at Hand increased rapidly after its introduction, reaching 49 000 by April 2019. Registered patients are younger, more educated and affluent and healthier than on average in London and England. For example, 81% of people registered are aged 20-39 years vs. 35% in London. Except for asthma, age- and sex-adjusted prevalence of common chronic diseases are 30% to 55% below the national averages. Older people and people with complex health needs and are less likely to register.

An online application, which includes a so-called *symptom-checker* linked to a triage system that recommends a course of action (e.g. to book an appointment, to go to A&E) but no diagnoses, provides the first point of contact for patients. Patients can also opt to book remote consultations without using the symptom checker. Remote consultations by phone or video are available around the clock, usually within two hours. Face-to-face appointments are offered at five clinics across London but, with exceptions for some services, patients are generally required to book a remote consultation first, which may then result in a face-to-face consultation. A multidisciplinary care team, led by a full-time care coordinator, is available to complex patients but only actively managed 51 patients as per early 2019.

Physicians can conduct remote consultations from home or from a physical hub in London. GP at Hand is funded in the same way as traditional primary care practices in England, through risk-adjusted capitation, and Babylon Health receive a portion of the funding for providing the digital infrastructure. Patients that register with GP at Hand are automatically deregistered from their prior practice. GP at Hand has a larger catchment area than traditional practices that only serve the population in their immediate vicinity; anybody who can access one of the five clinics within 40 minutes' travel time can register, effectively extending the catchment area to much of greater London. In February 2019, NHS approved a request for the service to be extended to the city of Birmingham.

An evaluation of the first two years of operation was published in May 2019, based on a patient experience survey, qualitative case studies of service delivery, and analyses of service utilisation and economic impacts using routine data. Effectiveness in terms of health outcomes and cost-effectiveness were not evaluated.

The evaluation found that remote consultations with physicians were the most popular services, especially shortly after registering with the practice and by phone rather than video, followed by use of the symptom checker and face-to-face physician consultations. People are attracted to the practice by the ease of accessing services – approximately 40% of remote consultations occur outside of regular business hours and patients report appreciating quick responses, not needing to take time off work and relatively short travel times to face-to-face consultations. Patients were found to be satisfied with the quality of services, with 90% stating that it was 'good' and 60% that it was 'very good', which exceeded satisfaction in a matched control group. Approximately 70% reported that quality of care was better than at their previous primary care practice. GP at Hand patients are more intensive users of emergency services and NHS telephone support than the national average, but use of such services was found to decrease after registration, suggesting that the primary care service may substitute some emergency services. However, because of the lack of a control group, it is not clear if such use may also have decreased with registration at a traditional primary care practice.

The main concerns raised by professionals and patients surveyed were related to the suitability of the service for patient with complex needs and potential loss of continuity of care. Other concerns include the appropriateness of the funding through the traditional risk-adjusted capitation formula, and the overall financial impact on the NHS given that a large physician workforce provides around-the-clock services to a relatively young and healthy patient population.

Source: Based on Ipsos MORI et al. (2019[77]) "Evaluation of Babylon GP at hand: Final evaluation report", https://www.hammersmithfulhamccg.nhs.uk/media/156123/Evaluation-of-Babylon-GP-at-Hand-Final-Report.pdf.

Ensuring equity is a challenge

Equitable access to enabling technologies and special support for people with lower digital and health literary are key prerequisites for tele-medicine to achieve its goals of increasing equity and efficiency. In addition, patients need to trust that the data transmitted by digital technologies are safe. These prerequisites are not always met in existing examples of care delivery models that feature tele-health technologies.

In many OECD countries, broadband internet access is more common in households in urban areas than in rural areas and in households with higher incomes (OECD, 2019[78]) (also see Section 2.4.2). The Gesundes Kinzigtal program in Germany (see Chapter 8 on system governance, stewardship and resource allocation for details), for example, struggled with insufficient IT infrastructure in remote areas and a large proportion of the population targeted, especially elderly people, were reluctant to adopt technologies, also due to lack of trust in data security (Melchiorre et al., 2018[22]). The review by Castle-Clarke (2018[73]) of ICT used in health care in the United Kingdom, including technology for remote delivery of services, found that people have limited knowledge of how data collected through ICT are used by the NHS and other organisations, which may be a cause of mistrust.

Unequal access to and use of ICT can lead to services be taken up by people with lower need, causing a misalignment between need and resource allocation. In England, for example, providers increasingly offer remote primary care services. GP at Hand (see Box 2.7) is mainly used by young and well-educated professionals but few patients with complex needs. Critics argue that use by mainly healthy and low-risk populations may divert resources away from people with higher need (DigitalHealth, 2018[79]; Oliver, 2019[80]; Iacobucci, 2018[81]), causing negative effects on efficiency and equity.

2.4. A strategic approach is needed to planning scalability and sustainability of new was of delivering care

Innovative ways of delivering health care and supportive ICT are most often tested in pilot or research projects, with project-specific funding. But many fail to be scaled beyond the initial project phase even if they are promising or prove to be successful. There are a number of common challenges to the broad implementation of new ways of delivering care including financial, technological and cultural factors as well as change management more broadly. Overcoming these requires a holistic approach to design, planning, evaluation and implementation of projects, with an ultimate goal of scaling up successful projects and discontinuing unsuccessful ones.

Data quality is a cross-cutting concern that affects all types of secondary use of data and ICT-supported care delivery because data-driven health care and decision making are only as good as the data they are based on. Effective and efficient delivery of care requires reliable, accurate and timely information as well as effective use of ICT to produce knowledge and action. An OECD survey on the readiness of EHR data for secondary use showed that data quality remains a key concern and suggested a number of mechanisms countries can use to improve quality, including legal requirements, auditing and financial incentives (Oderkirk, 2017[82]). A report by the RAND Corporation identified poor data quality as well as a lack of data related to social determinants of health as particular barriers to progress in using data for the coordination of care for complex patients (Rudin et al., 2017[37]). Continued investments in data infrastructure, governance and quality therefore need to accompany new ways of delivering care.

2.4.1. An overall ICT strategy can guide design of individual projects and facilitate their scale-up

Countries that lead the way in adopting ICT to improve care delivery typically have instituted an overarching national or system-level digital strategy to guide individual projects (also see Chapter 8 on system governance, stewardship and resource allocation). Strategies often comprise mechanisms to select and fund innovative projects, to pilot new ways of care delivery and evaluate their effects and costs, and to scale-up successful projects. Strategies can catalyse the adoption and integration of innovative ways to deliver care without excessive disruption (Gray Steele et al., 2016[20]). They can also facilitate cooperation between providers, payers and the technology industry to encourage the development and implementation of ICT tools that meet patient and provider needs. The latter is key to implementing integrated care for complex patients (Melchiorre et al., 2018[22]).

As part of its digital health strategy, the Israeli Ministry of Health opens so-called *challenge tenders* to fund, implement and evaluate innovative ICT solutions in health care. In contrast to classical tendering in public procurement, in which specifications of the features of a solution are defined upfront and the most advantageous bid that meets specifications is then selected, challenge tenders do not prescribe an approach to tackling an issue. Rather, they broadly call for creative thinking in proposing technological solutions that may address a small or large part of an issue. For each of the challenges for which the Ministry opens a tender, it also leads efforts beyond the digital realm to tackle the problem systemically. Challenge tenders seek digital solutions that support the overall effort. Further information on the tendering process is in Box 2.8.

Box 2.8. *Challenge tenders* in the Israeli health system

The Israeli Ministry of Health launched a new funding and evaluation mechanism in 2016 for innovative ICT solutions to 'challenges' identified in the health system, referred to as *challenge tenders*.

Challenges are identified by the Ministry of Health through public consultations and interviews with stakeholders in the health system (for example, senior staff of the Ministry, HMOs and provider organisations). Challenges that are considered particularly amenable to ICT are prioritised by the Ministry. Tenders then involve two main stages.

In the first stage, the Ministry of Health only specifies the problem to be solved and private firms are asked to propose possible solutions. This gives the Ministry of Health visibility of the technologies that are available to help solve the problem at hand. The Ministry chooses possible solutions from these proposals.

Solutions selected in the first stage are presented to possible piloting organisations in the second stage to match a solution with a health care organisation and launch a pilot project. Pilots can be run at various levels of the health system, for example at an HMO or an individual hospital. More detailed specifications are defined at this stage in collaboration with the organisation that will host the pilot, including an update of key performance indicators (KPIs) for the solution.

To widen the range of potential solutions and encourage bids by innovative start-ups and other firms that are inexperienced with public procurement, the administrative and legal frameworks have been softened for challenge tenders. There are currently more than 500 health IT firms in Israel, many of which are small. While tenders are currently open to Israeli firms only, the Ministry plans to open them internationally in the future.

The Ministry of Health funds licensing, development, integration, project management and deployment of the solution at the piloting site. The piloting site funds local hardware, development and integration that is specific and may be needed on their side. The Ministry and piloting sites collaborate in evaluation and measuring the effectiveness of the solution based on KPIs defined in the tender.

Among other areas, solutions selected through challenge tenders are currently piloted for preventing medical errors that result from errors in patient identification and to prevent falls in the elderly population. Tenders may identify solutions from other sectors of the economy and result in a pilot of their applicability to health care. For example, in addition to a mobile application using technology similar to barcodes, biometric facial recognition algorithms used in the banking sector are implemented for identification of patients in hospitals. Digital solutions for preventing falls include portable sensors that people wear at home for real-time monitoring and analysis of the risk of falls and a range of tools, such as 'smart' treadmills, that help train people to improve their balance and stability.

Scaling to the national level is intended for successful solutions. Solutions are selected for scaling and long-term engagement with the Ministry only upon successful completion of a pilot, based on KPIs and projections of need for the solution and its costs. This stage has not been reached yet.

Source: Israeli Ministry of Health, personal communications.

2.4.2. Financial, technological and cultural barriers commonly impede broader adoption of new ways of delivering care

New models of care delivery also require new payment mechanisms

New ways of delivering care, by definition, require new processes and workflows. A recurrent barrier to scaling these innovations is insufficient funding or financial disincentives for adopting the new way of working. To overcome this, provider payment mechanisms need to be aligned to encourage care coordination and the use of supporting ICT. This requires a move away from fee-for-service (FFS) payments.

Alternative provider payment mechanisms, such as bundling, capitation and pay-for-performance, can play an important role in facilitating the adoption of new ways of delivering care (see Chapter 8 on system governance, stewardship and resource allocation for further discussion on provider payment). In Australia, for example, the Health Care Home (HCH) for patients with chronic and complex conditions described above deliberately deploys bundled payments instead of FFS (the conventional provider remuneration mechanism in Australia). Participating primary care practices that take overall responsibility of a patient's care receive a monthly payment per patient to cover all care related to the chronic condition(s), including planning and review, and coordination of care (Health Policy Analysis, 2017[40]).

However, funding also needs to recognise up-front costs of designing and implementing ICT, and provide incentives or direct investment for implementing ICT tools that can increase effectiveness and efficiency of services at the margin. Up-front costs for designing and implementing ICT tools that support innovative care delivery are typically high while marginal costs of using them are usually low (sometimes approaching zero). For example, purchasing software might incur a one-off cost or annual license fee irrespective of whether it is used with 1, 10 or 1 000 patients. Additional funding may be necessary to cover initial implementation costs and relieve providers of some financial risk related to such investments. Sufficient upfront funding for new ICT tools can encourage innovation and finance necessary training and support for professionals and patients to facilitate implementation (Melchiorre et al., 2018[22]).

In scaling the GMA tool in Spain, the national Ministry of Health, Consumer Affairs and Social Wellbeing (MSCBS) funded the initial implementation of the tool in the various Spanish regions that manage their health systems autonomously. Ongoing costs of operating and using the tool are borne by regional health authorities.

In Canada, new care delivery models and services that rely on ICT are overseen and funded by Canada Health Infoway (also referred to as *Infoway*), an independent, not-for-profit organisation created and funded by the federal government. Infoway acts as a strategic investor, funding projects with provincial and territorial governments on a shared-cost basis, typically on a 75:25 ratio. Requests for proposals by provincial and territorial health departments adhere to defined criteria and milestones and all projects that receive Infoway funding are subject to an independent evaluation. Infoway has also directly designed, developed and implemented new ICT services, with 100% federal funding (such as PrescribeIT, an e-prescription system).

Interoperability and shared infrastructure enable scale-up of new ways of delivering care

Inadequate ICT infrastructures and limited interoperability of various tools are a common barriers to better integration of existing health care services (Melchiorre et al., 2018[22]). For example, among 101 innovative models of care for multi-morbid patients in Europe that use at least one ICT tool reviewed by Barbabella et al. (2017[23]), the scale of more than three-fourths remained local or regional and only about half were integrated into the wider health system.

Locally developed ways of care delivery and supporting ICT tools that are not interoperable with existing ICT infrastructures risk fragmenting care further rather than help integrate it and will also hamper scale-up of new ways of working beyond the local context. ICT tools that are developed in isolation for individual

diseases also pose similar risks of further fragmentation of care for multi-morbid patients. Regulation and project funding mechanisms can set requirements for new ICT tools with respect to data standardisation, interoperability with other tools and their suitability for existing ICT infrastructures. These levers are typically best embedded in a national data governance and policy framework.

Skills need to evolve and cultural change be managed

Another significant issue pointed out in previous studies of ICT-supported care delivery is the lack of ICT skills among patients and professionals (Melchiorre et al., 2018[22]). Cultural factors, such as general resistance to change or professional autonomy, can also hamper adoption of new tools and new ways of working. User involvement and designing new care pathways and tools that do not add to the workload of professionals and self-care burden of patients are one way of reducing cultural resistance. Their involvement can also help create a sense of ownership and ultimately encourage uptake of the solutions.

In addition to a data governance framework that ensures data privacy, new tools also need to be accompanied by appropriate training programs, technical support and change management processes, in particular for health care professionals. While skilled professionals can lead the way in making patients more comfortable with new processes and technology, a lack of skills may reinforce cultural resistance to using ICT tools as a routine way of working (ibid., also see Chapter 4 on the health workforce).

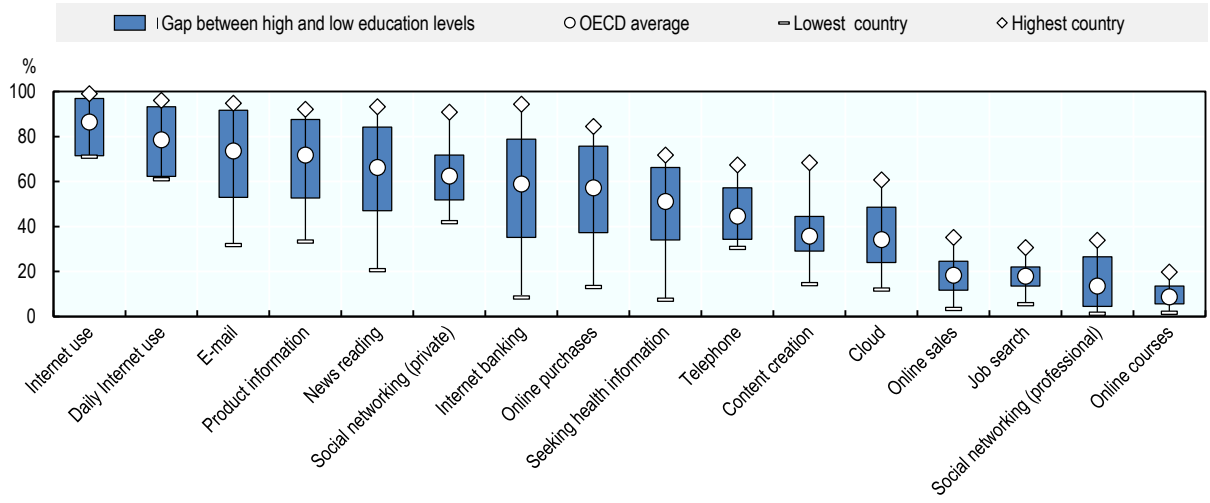
Policy should tackle persistent disparities in digital and health literacy

With nearly ubiquitous availability of mobile devices and internet connectivity, the digital divide may be ostensibly narrowing, but inequalities in internet access persist. On average across OECD countries, the number of mobile broadband subscriptions is close to the number of people in the population (OECD, 2019[83]). However, especially in OECD countries with lower incomes but also in some high-income countries such as Belgium, Germany and Luxembourg, there are fewer subscriptions than people in the population (ibid.). Broadband access is more common among households in urban areas and with higher incomes (OECD, 2019[78]).

Significant inequalities in digital skills are also observed. As internet connectivity improves, related factors that inhibit adoption of ICT among high-need populations may gain in importance. Even if they are connected, population groups with high health need may still be disadvantaged in terms of their capacity to use ICT. People aged 55-74 were less likely than those aged 16 to 24 to use the internet in every OECD country for which data were available in 2016 (OECD, 2019[78]). Data on adult competences suggest that on average, 32% of those aged 55-65 have no computer experience or have failed core ICT tests, compared with just 5% of 16-24 year-olds (OECD, 2017[84]). The King's Fund reports that about one-fifth of the United Kingdom population lack basic digital skills, in particular people in lower socio-economic groups (Castle-Clarke, 2018[73]). Figure 2.1 shows inequalities in the diffusion of online activities between people with high and low education levels in the population and between OECD countries.

Figure 2.1. Socio-economic disparities in online activities

Diffusion of selected online activities among individuals aged 16-74 in OECD countries, 2018.



Source: OECD ICT Access and Usage by Households and Individuals database (OECD, 2019[78]).

Poor digital literacy among high-need populations is one of the factors that impede the effective use of health-related ICT. A recent literature review on adoption of health-related applications in typically underserved populations,[9] for example, found that the main barriers to adoption were low health literacy and lack of experience with using ICT; difficulties in accepting the presented information, for example, because it was considered not useful, confusing or contradictory to users' own experience; and user-unfriendly and poorly designed interfaces (Huh et al., 2018[85]).

Foundational skills related to digital technology but also health literacy in all population groups, and in particular among the most vulnerable, are a key prerequisite for ICT-enabled care delivery to meet its goals. This is particularly true for care delivery supported by patient-interactive ICT, such as patient portals, remote monitoring or self-care devices. More broadly, further investments are needed to develop skills related to digital technologies and health literacy. These include offering incentives for and easing access to adult learning and improving the recognition of skills acquired after initial education so that everyone can participate in a digital society. Of course, more 'upstream' interventions such as social policies that support mobility and redistribution can also reduce digital divides.

Digital literacy is promoted by broader policies that aim to help people benefit equitably from an increasingly digitised economy. The Framework for Policy Action on Inclusive Growth (OECD, 2018[86]), which is part of the OECD Inclusive Growth Initiative, aims to help governments ensure a more equitable distribution of the benefits from economic growth along three major axes:

- Investing in people and places that have been left behind, which highlights the promotion of life-long learning and the acquisition of skills, increasing social mobility, improving health and enhancing access to affordable housing, promoting regional catch-up and investing in community well-being. This requires ongoing financial commitment.
- Supporting business dynamism and inclusive labour markets, which underscores the need to improve technology diffusion, innovation and entrepreneurship, as well as resilient labour markets and good jobs for all.
- Building efficient and responsive governments, which advocates for good governance and people-centred digital government strategies, as well as a whole-of-government approach to policy development and implementation.

2.4.3. Pilot projects need to be evaluated rigorously to select successful ones for scale-up

Another barrier to successful scaling of new ways of delivering care is the lack of rigorous evidence of their effects in terms of health outcomes and costs. Especially evidence of the effects of new ICT, which is an enabler of new models of care, is often lacking (Safavi et al., 2019[87]).

In order to make investment decisions that improve health system performance and make care more efficient, pilot projects need to be evaluated rigorously and only successful ones should be sustained and scaled up. Evaluation should be an integral part of project implementation. In Germany, for example, the Innovation Fund of the Joint Federal Committee (G-BA), the highest decision-making body of the self-governing associations of health professionals, hospitals and social health insurers, finances projects that pilot innovative ways of delivering care. There is a legal requirement that projects that receive funding be evaluated and that successful ones be scaled up nationally. Projects are currently still in the pilot phase.

Routine health data should be deployed to evaluate care delivery

Rigorous methods, such as cluster-randomised controlled trials or case-control studies that rely on routine health care data, can be used to evaluate new ways of delivering care and supporting ICT tools in terms of their effects on process-related or health outcome measures. Where possible, evaluations should be conducted by independent parties who do not have a vested interest in the success of a new care delivery model or ICT tool. This can help avoid bias, and reduce the risk of non-publication of negative findings.

Evidence on ICT-enabled care delivery is currently building. But the evidence base in terms of health outcomes is still limited in several fields of application of ICT and cannot be generalised easily, for instance in remote patient monitoring (see Section 2.3.4 and Noah et al. (2018[63])). Evaluation methods are not always rigorous and pre-post studies without control groups are common. Rigorous evidence is also scarce on projects that make secondary use of clinical data to generate knowledge for improving health care. A recent literature review concluded that many studies report how secondary use of data *should* impact care processes, health outcomes, productivity and costs rather than actual effects (Meystre et al., 2017[88]). Pilot studies of health-related ICT tools have often yielded little evidence to guide further implementation and scale-up of these technologies (Wilson et al., 2018[89]). Where evidence is available, it can be difficult to interpret and to use for decision-making because of varying terminology, design of interventions and rapidly evolving technology (Shaw, Hines and Kielly-Carroll, 2018[24]).

Qualitative process evaluation can complement quantitative studies of effectiveness. Process evaluations can help, for example, distinguish reasons for failure of achievement of desirable outcomes between: (1) implementation failure or (2) the failure of the intervention itself (Maar et al., 2017[90]), which is particularly helpful in learning from failures of complex interventions that may fail for a variety of reasons. Identifying the main factors that caused success or failure can also help make adjustments to care delivery and ICT tools. This is particularly important in the development of ICT tools that are user friendly and support person-centred health care, which requires iterative approaches.

It is therefore key that health systems continue to evaluate new solutions and that evaluations be embedded in project implementations. Where possible, evaluations should make secondary use of existing data to produce results quickly and cheaply (also see Chapter 7 on biomedical technology). They should combine rigorous quantitative methods to assess effectiveness with qualitative research to explore the reasons for the results observed and help make adjustments to new ways of working and supporting ICT tools. Doing this well requires building (and investing in) the necessary technical and policy capacity.

A fit-for-purpose approval and regulation model may be needed

For health-related ICT tools, which can be developed in iterative processes that allow for changes and improvements to be made as soon as deficiencies become apparent, different evaluation methodologies might be needed than for medicines or medical devices. An agile and user-centred research and development cycles have been proposed to adapt the current 4-phase regulatory approval process for medicines and also allow for continuous and iterative development and incorporates development and testing processes typically used for ICT (Mathews et al., 2019[91]; Wilson et al., 2018[89]). Importantly, this approach would allow for limited market releases of ICT tools that are proven safe to test their effectiveness while allowing for replacement of existing versions by subsequent iterations as these become available (ibid.).

The US Food and Drug Administration (FDA) is currently implementing its Digital Health Innovation Action Plan. Under the plan, the regulatory agency is formulating new standards for mobile medical apps, tele-medicine and software as a medical device (SaMD), among other digital health technologies, to reduce delays in access to lower-risk technologies while ensuring safety and effectiveness of regulated technology.

2.4.4. Design of ICT tools should involve end users

As end users of new ICT tools, both patients and providers need to be involvement in their design because such tools have an indirect effect on care through altering workflows between professionals and in patient-provider interactions (Shaw, Hines and Kielly-Carroll, 2018[24]). Patients, in particular, may have different priorities from ICT firms, providers and payers, and therefore need to be represented in the development and implementation processes of ICT tools that support their care (Cohen et al., 2014[92]). Organisations need to establish learning mechanisms that allow patients and providers to identify incremental, progressive adjustments and feed those back to developers for improving ICT solutions (Shaw, Hines and Kielly-Carroll, 2018[24]).

Harnessing the collective wisdom of users in the design and implementation of tools is likely to make them more successful (Shaw, Hines and Kielly-Carroll, 2018[24]). Equally, novel technologies are likely to be successful only if they clearly reduce patient inconvenience and burden, helping them to accomplish their "illness work" more efficiently and effectively (Ancker et al., 2015[75]). For instance, a lack of harmonisation of digital health interventions with clinical pathways and existing systems may disrupt workflow. This in turn could lead to adverse effects on usability, accentuated implementation complexity and reduced patient safety. Secure messaging between consumers and clinicians has the potential to improve patient safety and quality, but may concurrently increase clinicians' workload considerably, and impede their ability to respond to messages on time. Such effects on workflows need to be considered in the design of tools, to integrate them into workflows to support uptake and, ultimately, achieve positive outcomes.

Operational problems with many EHRs platforms are well documented. In some cases EHRs are so user-unfriendly that some physician practices employ scribes to enter information into the record while the provider interacts with the patient (Coiera et al., 2018[93]). The lack of practical functionality has several causes, including lack of user engagement in the purpose and design of the electronic platform and its interface. In the United States, the Department of Health and Human Services (HHS) is currently establishing a strategy to encourage the electronic exchange of health information by reducing the administrative burden of using EHRs and other health-related ICT. The strategy revolves around three overarching goals: reducing the effort and time required to record health information; reducing the effort and time required to meet regulatory reporting requirements; and improving the functionality and intuitiveness of EHRs (ONC, 2018[94]).

The Electronic Patient-Reported Outcomes Tool (ePRO) in Canada, for example, was developed in an iterative approach involving user groups of patients and primary care physicians (Steele Gray et al., 2016[95]). This is an innovative approach to designing mobile health technologies that meet patient needs and can be integrated into the care process. The tool allows providers and patients with complex chronic

health needs to define and monitor patient-care plans to improve patient self-management and supports information sharing as well as shared decision-making between primary care physicians and other providers (ibid.). It is currently undergoing evaluation by randomised controlled trial to be completed in November 2019 (Steele Gray et al., 2016[96]).

2.5. Conclusion

This chapter demonstrates that new ways of delivering health care supported by ICT have great potential to transform health care, making health systems more effective in improving population health, more equitable and more efficient in their use of resources. These goals can be achieved through harnessing ICT and electronic data to (a) redesign health services according to health needs of individuals and groups and (b) deliver these services in an integrated and patient-centred way.

The increasing number of patients with complex needs in OECD countries, who need health and social care services from several providers and over prolonged periods of time, stand to gain the most from new models of care delivery that use ICT. Digital technologies can help identify such patients, inform them about their own health and care, improve communication and coordination between them and their providers, increase the accuracy of diagnoses and clinical decision making, and help monitor their health remotely and deliver appropriate services across geographical distances.

However, a number of pitfalls need to be avoided if innovative and ICT-supported care delivery is to be effective, especially at scale. Importantly, ICT tools should not be seen as interventions in their own right – they are enabling tools that can alter and improve workflows in care delivery and need to be designed and implemented accordingly. Without an overarching ICT architecture that ensures that new tools are interoperable and can be integrated with existing information systems and stand-alone solutions for specific diseases, ICT can entrench and even exacerbate fragmentation of care rather than facilitate better integration. Policy also needs to ensure that ICT does not exacerbate inequity by favouring access to services by low-risk population groups with higher health and ICT literacy.

Secondary use of data is generally cheap, so greater use of existing data to generate knowledge and improve services can often be a highly cost-effective way of improving health outcomes. But this does not necessarily imply cost savings. The use of data and ICT can, for example, uncover unmet need and make new models of care delivery and digital services more accessible, increasing demand. This can lead to increases in aggregate expenditure. However, such cost implications should be seen in the context of (a) potentially improved health outcomes in vulnerable populations, and (b) reduced utilisation costs over the longer term. As with all technologies that generate and/or use personal health data for, ancillary and ethical concerns need to be managed.

Many OECD countries still appear to be far from realising the potential of ICT in transforming care delivery. The systematic identification of complex patients, system-wide efforts to integrate information systems to support integrated care delivery, making digital data and information accessible to patients and professionals, and truly integrated and knowledge-based care delivery models are still the exception rather than the rule. Only few countries report that the development of new and ICT-supported ways to deliver care target complex patients. Many ICT tools and models of care delivery described in this Chapter are local pilot projects, which, while promising, are yet unproven. In particular, rigorous evidence of the effectiveness and efficiency is still sparse. Countries with most success in this area have an overarching digital strategy and an integrated information infrastructure with a strong focus on interoperability through strong data governance.

It remains a challenge for health systems in OECD countries to evaluate innovative ways of working, discontinuing those that are ineffective or provide poor value for money and ensure that those, and only those, that prove successful are scaled up.

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Notes

[1] The terms ICT and digital technology are used interchangeably in this Chapter and throughout this Report.

[2] Austria, Belgium, the Czech Republic, Denmark, France, Germany, Italy, Spain, Sweden, and Switzerland.

[3] Whereas *precision medicine* is defined as refining the understanding of disease prediction and risk, onset and progression in patients, to inform better selection and development of evidence-based and targeted therapies and associated diagnostics. This is achieved by taking into account the patient's genomic and other biological characteristics, as well as health status, medications patients are already prescribed and environmental and lifestyle factors (OECD, 2017[97]). Both, precision medicine and personalised care are heavily reliant on evidence derived from secondary use of real-world or routine data.

[4] See, for example, Cainzos-Achirica et al. (2018[98]), Cancio et al. (2018[99]), Miquel et al. (2018[101]) or Vela et al. (2018[100]).

[5] For further discussion regarding the opportunities and risks of engaging patients with data, see Chapter 3 on *The informed patient.*

[6] See https://echo.unm.edu.

[7] Although the terms *tele-medicine* and *tele-health* are often used interchangeably, tele-health is broader than tele-medicine and encompasses any use of ICT to promote health, including non-clinical services. See Cravo Oliveira Hashiguchi (forthcoming[62]) for definitions and an overview of the broader e-health ecosystem that includes tele-medicine and tele-health.

[8] See www.headtohealth.gov.au.

[9] Including people among racial/ethnic minorities in the study context of the country; with lower educational attainment and literacy; facing economic barriers to accessing health care, e.g. as a result of employment status, poverty or insurance status; and people living in geographically isolated areas.

3 The informed patient

Elina Suzuki

An informed and engaged patient is critical to creating a people-centred, sustainable health system. Across the OECD, patients are increasingly turning to new technologies to gather health information, using tools from both within and outside the health system. Physician consultations and electronic health records are far from the only sources of information for patients today. Patient engagement with new technologies is increasingly driven by tools outside traditional health data, with patients increasingly consulting the internet and using new health technologies to monitor and engage with their own health. These developments bring both significant opportunities and challenges for individuals and the health system more broadly. This chapter reviews how health systems users are interacting with new digital tools to engage in their own health, and how health systems are responding to these new developments to facilitate access to information and improve health and digital literacy for patients.

3.1. Introduction

Digital transformation improves how efficiently information is created, shared and distributed. It is credited with creating a considerable net consumer surplus across various sectors of the economy. In health, value can be generated through more effective and efficient sharing of information and knowledge with consumers – or patients.

An informed and engaged patient is critical to the success of achieving a people-centred, sustainable health system. The proliferation of digital technology is often touted as the way to achieve this ambition. Across the OECD, people are increasingly turning to new technologies to gather health information from both within the health system (e.g. electronic health records) and outside it (e.g. the internet and health apps). But is the hype of digital technology in health justified, and is everybody using the data, information and knowledge generated to manage their health and participate in their care to the same extent?

Patients today have access to nearly endless sources of information, ranging from their health care providers to online informative sites (e.g., WebMD). They are also equipped with more options to monitor and engage in their own health decisions than patients of the past. In many ways, this has made people today better informed about their own health than ever. But it has also made it increasingly difficult for many to discern what information and tools might be beneficial, what might have a marginal effect, and what may actually be harmful to their own, and others', health.

In response, many countries have begun to scale up efforts to provide patients and health systems users with information about their health. This information comes directly from their engagement with the health system and health professionals within it. Tools such as patient portals, when well designed, give health systems users direct access to information about their own health that would previously have been in the hands of health professionals, who acted as arbiters of what to share.

Recognising the importance of having adequate health literacy to make use of the information, countries are also scaling up efforts to improve health and digital literacy, including among disadvantaged populations.

While patient portals and health literacy efforts by countries are putting more power in the hands of health systems users, these efforts are also occurring at a time when more health information than ever is delivered through unstructured sources outside of the traditional health system.

This chapter reviews how health systems users are interacting with new digital tools to engage in their own health. It examines how health systems have facilitated access to information for patients and health systems users and how new digital tools *outside* of the health system are increasingly transforming how people take ownership of their health. The chapter examines both the real and potential benefits of putting more information and power in the hands of patients, while also considering new challenges that arising from the expansion of new digital tools for health.

3.2. Patients can access a growing number digital tools to engage in their own health

In terms of making information about their health and their care more accessible to patients, many health systems are moving in the direction. However, platforms such as electronic health records (EHRs) are often not designed with the patient (and also the health care providers) in mind. In addition, not all patients are making use of the access to their information. Evidence suggests that those with the greatest health need are also the least likely to access their records. Moreover, while the internet is a growing and influential source of health information, its use reflects traditional health inequalities that follow the socio-economic gradient. Smartphone health apps and direct-to-consumer (DTC) services can serve as useful adjuncts to inform individuals and patients, but their quality is often questionable and they create a new set of challenges for policy makers and health care providers.

The use of electronic health records has rapidly risen but the patient is often not the primary focus.

The use of electronic health records for patient engagement has been in many ways peripheral to the development of EHRs. The development of EHRs has been primarily driven to help improve clinical care, inform medical research, and – in many cases – to help streamline billing and other administrative processes in the health care system (Evans, 2016[1]). In recent years, there has been a rapid rise in the uptake of digital records for health. All OECD countries now use or are in the process of developing electronic health records, and 23 of 28 OECD and partner countries reported that they had implemented a national-level electronic health record system in 2016 (Oderkirk, 2017[2]). To avoid multiple EHRs being connected to one patient, nearly two-thirds of countries (18 of 28) have developed a single country-wide system for sharing health information (Oderkirk, 2017[2]).

Harnessing EHRs to improve patient involvement has not been the primary driver of their development. As a consequence, the structure and organisation of EHRs have frequently been designed without the patient as a user in mind. What may be of importance or interest to clinicians, researchers, and health systems administrators is in many cases not what information patients would find useful. Even if the information is relevant, it may not be presented in a format that makes finding or interpreting it easy.

To help facilitate patient engagement with digital health records, OECD countries are increasingly developing patient-oriented digital health platforms that present the information collected through digital health records in a more user-friendly, accessible format. The majority of countries (12 of 15) responding to a 2018 OECD Survey on Knowledge-Based Health Systems reported that patient portals have been launched or are in the process of being developed.[1] Portals typically include a subset of patient information collected through electronic health records, presented in a format that is more user-friendly and relevant to the needs of patients. For example:

- In **Finland**, the online patient portal *My Kanta* allows all persons with a Finnish personal identity code to access their health data online. Patients using *My Kanta* can access their medical record (such as physician's notes and nurse's reports) and electronic prescriptions, manage consents (including for data sharing and organ donation), and view the log history of how their data has been used. (Vehko, Ruotsalainen and Hyppönen, 2019[3]). As of the end of 2017, 53% of adults had accessed their *My Kanta* page, with about 600 000 monthly users, out of 2.4 million registered adults (Vehko, Ruotsalainen and Hyppönen, 2019[3]).
- In **Estonia**, all citizens are able to access their electronic health records and review medical data and initiate certain processes, including applying for a health certificate. An ongoing project in Estonia, *MyData*, will also allow patients to donate their health data to third parties to use for research purposes (OECD, 2018[4]).
- In **Luxembourg**, patients receive full access to their patient record, the *dossier de soins partagé* (DSP) once they have signed a care coordination contract with their physician. Physicians and patients access the same information in the DSP, including a patient summary, lab and imaging results, discharge letters, information provided by patients, and health services history (OECD, 2018[4]).
- In **Norway,** *Helsenorge* is intended to be the national health portal for citizens. *Helsenorge* consists of a platform (basic infrastructure) and various population oriented services including vaccine cards, switching GPs, overview of prescriptions, medicines, access to patient record, appointments, and e-consultations (included video), among other services (OECD, 2018[4]).
- In **Poland**, Patient's Internet Account (IKP) was introduced in 2018 within the "e-health Platform" (P1 Platform) project. IKP will enable every patient to access their personal health information, including prescriptions, referrals, orders for medical devices, benefits provided and their cost, the clinical decisions made by primary care providers, and medical leave. IKP will also enable the patient to authorise another person to access medical data or health information. Access to the IKP is granted with the use of e-banking identity profiles. IKP is being expanded with new functionalities with the aim of it becoming key point of contact between people and the health system (OECD, 2018[4]).

- In the **United States**, the 21st Century Cures Act requires health IT developers to build and make accessible to health care providers an API allowing patients access to their records "without special effort". HHS has developed regulations to implement these provisions for technology developers, health care providers, and public insurance payers to provide secure and more immediate access to health information for patients and their health care providers and new tools allowing for more choice in care and treatment. These regulations will help ensure that patients can electronically access their electronic health information at no cost. By supporting secure access of electronic health information and strongly discouraging information blocking, the rule supports the 21st Century Cures Act, which would support patients accessing and sharing their electronic health information, while giving them the tools to shop for and coordinate their own health care (OECD, 2018[4]).
- Enabling people to access their personal health information is a key part of the Swedish eHealth strategy (Box 3.1)
- In **Denmark** (which did not respond to the survey), the public eHealth portal, *sundhed.dk*, allows all citizens and health professionals to access data such as laboratory test results, electronic medical records, telemedicine home monitoring and medicine from the entire country. New services including appointments with the health care system, customised plans for chronic patients are being rolled out across the country. With more than 2.4 million unique users every month, *sundhed.dk* is the most used eHealth platform in Denmark, and is also available as a mobile app (OECD, 2018[4]).
- In **Portugal** (which did not respond to the survey), the Ministry of Health has created an online portal for patients, the *SNS Portal*, which allows registered users access their medical records, online prescriptions, schedule appointments, and communicate with health professionals (Tavares and Oliveira, 2017[5]).

Box 3.1. Enabling patient access to electronic health records: The Swedish eHealth Strategy

Since 2017, electronic health records for patients have been accessible in all 22 counties in Sweden. As of February 2017, nearly 40% of eligible patients (all residents 16 years and older) had registered for an account. Through their EHR, Swedish residents have access to information from health and dental services, including physician's notes, test results, vaccination histories, medications, referrals, and a history of who has accessed their online medical record. While residents cannot change the information in their patient record, they are able to add comments to flag where information may be incorrect (Armstrong, 2017[6]). Throughout Sweden, multiple electronic health records systems have been implemented. From the patient's perspective, however, the development of a national Health Information Exchange platform has allowed the multiple EHR systems to be consolidated, allowing a single record to be viewed by the user (Hägglund, 2017[7]).

Efforts to roll out access to electronic health records have come as part of Sweden's national e-health strategy, which has been developed to promote patient empowerment through involvement in their health and social care, as well as strengthen quality of care and decision-making among health and social care professionals. In addition to facilitating access to residents' health and social care information, the eHealth Strategy has also made it a priority to provide information important to health and social care systems users, such as quality and accessibility issues, in a user-friendly format. To strengthen the quality of long-term care for older persons, the platform also allows residents to authorise access to information related to their care, contained in a Care Diary, to family and friends who wish to monitor the care they receive on a regular basis (Swedish Ministry of Health and Social Affairs, 2011[8]).

Sweden has further monitored user response to the rollout of electronic patient records, to ensure the system is meeting the needs of its users. A national patient survey of users of the patient-accessible electronic health records (PAEHR) system, *Journalen*, found that overwhelming majority of users felt positively towards the system (Moll et al., 2018[9]).

3.2.1. Opt-out systems appear to be more effective in encouraging EHR adoption

Health data are among the most protected and valuable sources of personal information, and developing patient consent systems that allow users to make an informed choice about how their data are used and who they are shared with is of critical concern in the development of both electronic health records and patient-facing portals. This requires clear communication over the patient's authority over how their health data are used, and clear paths for them to manage consent related to their personal data.

Most countries have addressed the issue by providing patients with either the opportunity to opt in to using electronic health records, or automatically register patients, with the opportunity to then opt out of sharing their data.

Evidence from organ donation programmes indicates that systems that provide users with an opportunity to opt-in face significantly more hurdles in recruitment than systems which automatically enrol users, with an opportunity to opt-out where desired. A study of organ donation policies in 48 countries found that opt-out consent resulted in a relative increase in both kidney and liver transplants in countries that had implemented an opt-out organ donation policy, compared with those countries where opting in to the programme was required (Shepherd, O'Carroll and Ferguson, 2014[10])

Countries that have selected systems that allow patients to *opt out* of sharing their health information have seen relatively few users choose to do so. In 2014, 12% of Austria's population was expected to opt out of the country's patient portal when it launched in 2015. As of 2018, fewer than 4% of citizens have chosen to do so (Ammenwerth, 2018[11]). Finland has seen a similar prevalence of patient opt-out, with 90 000 of close to 2.4 million users opting to restrict some or all of their patient record from being shared (Vehko, Ruotsalainen and Hyppönen, 2019[3]). In Australia, the national patient portal, *My Health Record*, moved from an opt-in approach in its early years to an opt-out model, giving citizens until the end of January 2019 to opt out of the creation of a My Health Record. After this point, all citizens who had not opted out had a record created, although users retain control of how their information is shared and can delete the record in its entirety at any time (Australian Digital Health Agency, 2019[12]).

3.2.2. Uptake of electronic health records and patient portals is not even, and is low among high-need patients

Governments have made good progress in giving patients access to their own health information, notably through the expansion of electronic health records and patient portals. However, many of these platforms are underused. Even where patients have access to their health information through official platforms, engagement is far from guaranteed. In the United Kingdom, fewer than 8% of patients who were able to access their medical records actually did so (NHS Digital, 2019[13]).

Most concerning is the comparatively low uptake among the very patients who stand to benefit the most from a patient-centred approach. In the Netherlands, for example, just 4% of the chronically ill population reported using a personal health record (NICTIZ, 2017[14]). A 2017 study of patient portals in Estonia, Denmark and Australia suggested that monthly usage of patient portals was under 1% of the eligible population in Estonia and Australia, and under 5% in Denmark (Nøhr et al., 2017[15]). In Sweden, nearly 38% of the eligible population had set up an account to view their electronic health by February 2017, while 53% of eligible adults in Finland had accessed their EHR by the end of 2017 (Vehko, Ruotsalainen and Hyppönen, 2019[3]; Armstrong, 2017[6]).

Patient access to their electronic health records is a recent development in nearly all OECD countries; as awareness about EHR and patient portals increase, the number of people consulting their health records online is likely to increase, and it is likely at least some of the range in access rates reflects how long systems have been in place.

Not all users of the health system will benefit from more frequent engagement with digital health tools like patient portals

Patients with complex health needs who require frequent monitoring and close management stand to benefit most from systems that allow them to better monitor and engage in their health care. Results of a randomised control trial (RCT) of adults living with asthma suggested that patients who received internet-based self-management support had better quality of life, better control of their asthma, higher lung function, and more days spent without asthma symptoms, compared with adults who were not provided online self-management support (Van Gaalen et al., 2013[16]). Adults living with diabetes have also been found to have better process and clinical outcomes when offered online self-management tools in addition to usual care (Grant et al., 2008[17]).

A Canadian RCT found that patients who were given online self-management tools and telephone reminders for appointment visits and medication had more frequent visits with their physicians, more frequent risk factor monitoring, and better clinical outcomes on some measures (including blood pressure and haemoglobin levels), compared with those who did not receive the online self-management support (Holbrook et al., 2009[18]). A systematic review of interventions to strengthen self-management among adults with diabetes similarly found that online self-management programmes help to improve both clinical and behavioural outcomes (Nuti et al., 2015[19]).

Patients have also been found to increase the use of certain preventative health services when electronic reminders are sent through their online personal health records. A study of patients in the *Partners HealthCare* system in the United States found that patients who received online reminders were more likely to receive influenza vaccinations and mammography screenings than those who did not (Wright et al., 2011[20]).

However, it is far from clear that the patients who are most likely to access and use their health data are also those who stand to benefit the most from doing so. Numerous studies have suggested that access to patient portals continues to be uneven across different populations (Irizarry, DeVito Dabbs and Curran, 2015[21]; Singh, Meyer and Westfall, 2019[22]; Coughlin et al., 2018[23]; Gordon and Hornbrook, 2016[24]). People with better health literacy, more education, and non-minority patients – demographic and personal characteristics that reduce the risk of poor health – have been found to be both more likely to access patient portals, and more likely to use them more intensively.

In the United States, a study of patient portal use among older adults indicated that white patients, patients with tertiary education, and patients with higher health literacy were more likely to register for a patient portal account (Smith et al., 2015[25]). Other characteristics suggest that the patients who stood to benefit most from using the patient portals were less likely to access them. Patients with two or more chronic conditions were 30% less likely to register for an account than patients with no chronic conditions. Moreover, patients with higher health literacy were more likely to communicate with their physicians using their online portals, while patients with higher education were more likely to request the reauthorisation of existing prescriptions (Smith et al., 2015[25]).

A study of a diabetes registry in the United States found that older patients, black and Hispanic patients, and patients with lower-education were less likely to register for an online patient account, while lower-educated and ethnic minority patients were less likely to engage with their patient portal even if they had registered for it (Sarkar et al., 2011[26]).

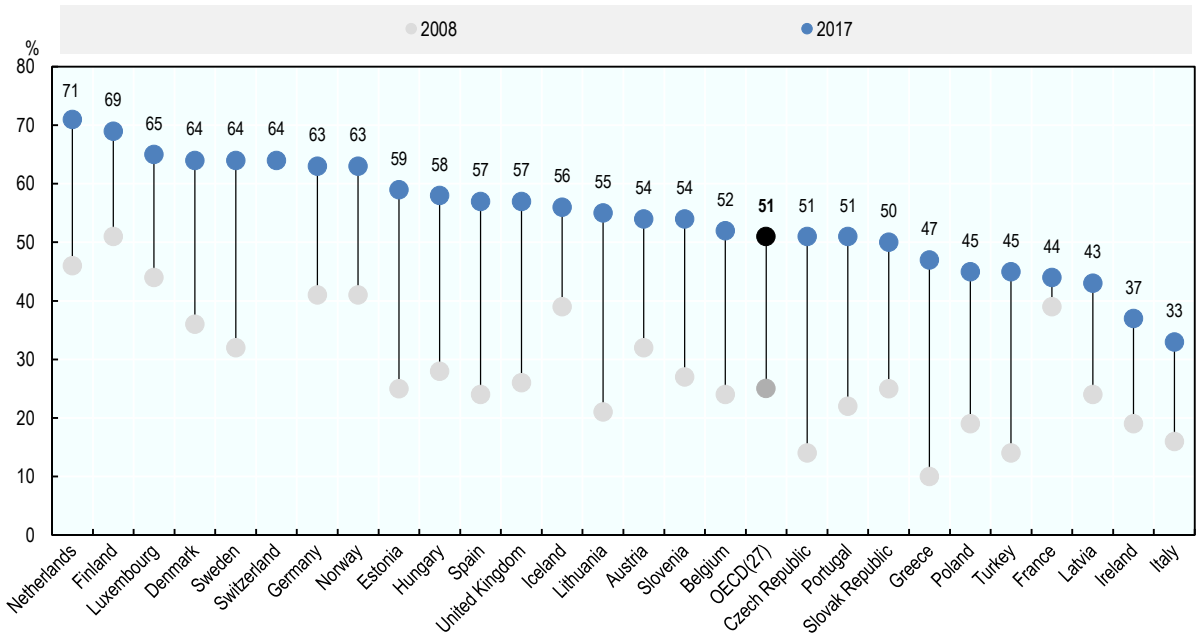
3.2.3. The internet is a growing and influential source of information for health system users

The internet has transformed how people interact and get information across their lives, including their health. It offers an unparalleled opportunity for health systems users to access information without filtering

by any type of traditional health system gatekeeper. Even information offered through patient portals and electronic health records, though in many cases arguably offering more personally applicable information, is filtered through the prism of what health systems and health professionals have found appropriate to share with their patients.

Patients are increasingly supplementing the information they receive from health professionals with information they find through online sources. Physician consultations and even electronic health records are far from the only source of information for patients today. Increasingly, patients consult the internet and use new health technologies (including apps and other devices) to monitor and engage with their own health. In OECD countries, the proportion of adults using the internet to search for health information nearly doubled between 2008 and 2017 (Figure 3.1).

Figure 3.1. Online health-seeking behaviour is increasing across countries



Source: OECD/EU (2018[27]), *Health at a Glance: Europe 2018: State of Health in the EU Cycle*, https://dx.doi.org/10.1787/health_glance_eur-2018-en.

The rapid growth in the proportion of people seeking out health information corresponds with a broader digital revolution that has transformed connectivity in the last decades. Between 2005 and 2018, the percentage of households with access to the internet increased by 80% across OECD countries, from less than half (47%) to nearly all (87%) homes in 2018. In 2018, three in five adults aged 25-54 across 33 OECD countries reported that they had sought out health information online in the previous three months. This represents a dramatic increase from just a decade earlier, when fewer than one in three adults reported having sought health information over the previous three months.

The internet offers health system users and patients a number of advantages beyond what they might be able to receive through traditional channels. Through sources such as PubMed, Google Scholar, and other academic repositories online, patients have unprecedented access to the clinical research that underpins much medical care. While they may not have the health literacy to interpret this information correctly, the ability to access this research represents a momentous shift in how information is distilled and shared with patients and the public. Prior to widespread internet access, for example, participating in clinical trials was largely dependent on the information health care providers shared with their patients.

Peer-to peer networking can offer value to patients and the public

Moreover, the advent of the participative Web ("Web 2.0") has allowed health systems users to find and exchange information with other interested participants much more easily and quickly than was previously possible. It is perhaps no coincidence that the 'patient voice' in health care has grown in the same era that has made it possible for patients to more easily find and stay connected with one another. Forums dedicated to specific diseases and conditions have enabled patients to exchange information and seek support from other people going through similar experiences.

The online patient community *PatientsLikeMe* offers an interesting case study in how an online forum for patients can also be harnessed for clinical research purposes. Started to connect patients with amyotrophic lateral sclerosis, *PatientsLikeMe* has since expanded to include more than 700 000 patients living with more than 2 800 conditions (PatientsLikeMe, 2019[28]). In addition to forums open only to registered users, where patients can share questions and experiences with others, the website offers tools to track their health, report outcomes, and seek information about different health conditions. In addition to the patient-oriented tools and information offered through the website, *PatientsLikeMe* sells all non-identifiable information about its members, including to academic research groups, advocacy organisations, and pharmaceutical companies for research purposes (PatientsLikeMe, 2019[28]).

Traditional inequalities persist despite these advances

However, there is evidence that many health inequalities – such as inequalities in health literacy and health-seeking based on socioeconomic status and level of education – are being replicated in how health systems users seek out health information online. In the United States, data based on the Health Information National Trends Survey (HINTS) has found that people with higher levels of education are significantly more likely to use the participative internet (such as Facebook, Twitter and other websites that allow users to actively engage) to find health information. People with a college education were found to be twice as likely to use the internet for health information than those without a high school degree, while adults with a post-graduate education were seven times as likely to seek out health information online, compared with people who had not finished high school (Tennant et al., 2015[29]).

3.2.4. Mobile phones and apps increasingly serve as personal health monitors

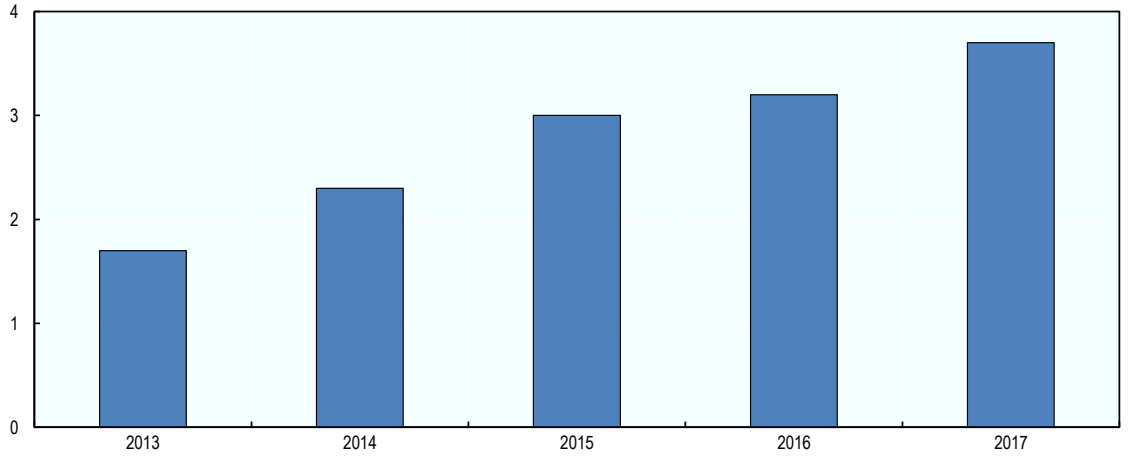
The rapid proliferation of 'mobile health' (mHealth) – most notably online, through social media, and through health apps and other software – has introduced new flows of information that are unrestricted, largely unregulated, and often unverified. Between 2013 and 2017, the number of mHealth app downloads more than doubled worldwide, from 1.7 billion to 3.7 billion (Figure 3.2).

More than 325 000 health applications are now available for consumers to download, with nearly one-quarter – some 78 000 apps – added in 2017 alone (Research2Guidance, 2017[30]). Wearable technologies, meanwhile, more than tripled in use between 2014 and 2018, with one-third of responding adults in seven countries (Australia, Finland, Norway, Singapore, Spain, United Kingdom [England], United States) reporting that they use wearable health technologies in 2018, compared with fewer than one in ten in 2014 (Safavi, K., Webb, K., Kalis, 2018[31]).

Increasingly, the source of new health technologies come from outside the traditional health sector. Traditional health actors – including insurers, pharmaceutical companies, hospitals, and medical device companies – release just over half (53%) of mHealth applications. The remainder (47%) of health apps released are developed and released by companies that are focused exclusively on the digital market (Research2Guidance, 2017[30]).

Figure 3.2. Interaction with mHealth applications has risen quickly

Billions of downloads per year



Note: Data for 2017 are preliminary estimates.
Source: Research2Guidance (2017[30]), "mHealth Economics 2017: Current Status and Future Trends in Mobile Health", https://research2guidance.com/product/mhealth-economics-2017-current-status-and-future-trends-in-mobile-health/.

The rapid rise in the number of consumer-oriented health applications, and the influx of new non-health actors into the creation and delivery of these digital tools, raises important questions related the quality, effectiveness, and efficiency of many of these new applications. The sheer number of digital tools available to users – quite literally at their fingertips, through mobile phones – can make it difficult to identify which apps and tools are actually effective, which might be marginally useful, and which could in fact be harmful to health. Some countries are taking steps to improve information around the quality of consumer-oriented health applications (Box 3.2).

Box 3.2. Improving consumer information: The NHS Apps Library

In the United Kingdom, the National Health Service (NHS) has taken steps to improve information around the quality of consumer-oriented health applications by developing an online *NHS Apps Library* toolkit. The website provides information about free and paid health apps that have undergone a digital assessment by the NHS. Apps are evaluated by an expert group based on a set of Digital Assessment Questions designed to evaluate products based on evidence on outcomes, clinical safety, data protection, app security, usability and accessibility, interoperability, and technical stability.

The digital assessment undertaken by the NHS is intended to incorporate standards for digital health technologies set by the National Institute for Health and Care Excellence (NICE). NICE most recently published an updated *Evidence Standards Framework for Digital Health Technologies* in March 2019. The guidelines are intended to inform the development of digital health technologies by developers, by setting the evidence standards expected for technologies to "demonstrate their value in the UK health and care system," as well as inform decision-makers when considering whether to commission new digital health technologies.

More than seventy apps are currently available through the NHS website. In addition to a short summary, the NHS Apps Library indicates where apps have been evaluated and approved by NHS, lending credibility to the claims made by the app designer. The app library can help consumers to narrow down the choices for health-related apps that are available to them through broader app repositories on mobile phones.

Source: NHS (2019[32]), NHS Apps Library, https://www.nhs.uk/apps-library/; NICE (2019[33]), Evidence Standards Framework for Digital Health Technologies Contents, https://www.nice.org.uk/about/what-we-do/our-programmes/evidence-standards-framework-for-digital-health-technologies.

Most tools are developed without input from medical experts

Studies of apps aimed to improve a range of health conditions and behaviours suggest that, in the majority of cases, apps have been developed either without the involvement of health care professionals, or without the transparency to determine how they were developed. In a survey of free health apps intended to improve medication adherence, researchers found that just 12% of available apps had been developed with the involvement of health care professionals, while just over 1% of apps documented any kind of evidence base for their product (Ahmed et al., 2018[34]).[2]

Research into consumer-facing health apps and technologies for specific health conditions have found similarly troubling results: Evaluations of smartphone health applications for colorectal conditions, urology, obesity surgery, microbiology and dermatology have all found that far fewer than half of all available apps included a health care professional in their development (O'Neill and Brady, 2012[35]; Carter et al., 2013[36]; Pereira-Azevedo et al., 2015[37]; Stevens et al., 2014[38]; Hamilton and Brady, 2012[39]).

The data deluge introduces some new challenges

The increase in health apps and wearable devices also offers unprecedented information on the consumer-patient. The technologies embedded within digital devices used on a daily – if not near constant – basis can collect highly detailed, extremely valuable information on the behaviours of individuals. As just one example, modern Apple iPhones automatically include a built-in Health application that tracks the distance the user walks in a day.

In most cases, health systems are still struggling to figure out how the information offered through non-traditional health data sources, including apps and smartphones, can be integrated with traditional sources of data to generate a richer picture of the health and behaviour of health systems users. This challenge introduces a number of important challenges that highlight the ethical, technical, security and privacy considerations that must be taken into account when patient data is at stake. Concerns have been raised that integrating consumer-generated data into EHR together with information from electronic medical records raises the likelihood that inaccurate information could be recorded in the patient's health record (Singh, Meyer and Westfall, 2019[22]).

3.2.5. Direct-to-consumer (DTC) medical testing presents challenges

Over the last decade, the number of consumers undergoing genetic testing through DTC tests has risen exponentially. Sales of DTC genetic tests reached USD 99 million in 2017 and are expected to quintuple by 2023 (Storrs, 2018[40]). It is estimated that 12 million people – including 1 in 25 people in the United States – had taken a DTC genetic genealogy test by 2018 (Regalado, 2018[41]). In addition to information about ancestry, DTC companies offer consumers the opportunity to directly receive health-related information based on their personal genetic profile. 23andMe, one of the largest DTC genetic testing companies in the United States, offers consumers more than ten health reports, including the genetic risk for breast and ovarian cancer based on the BRCA1/BRCA2 gene, the genetic risk for certain forms of Alzheimer's disease, and the genetic risk for Parkinson's disease (Table 3.1).

However, concerns have been raised over whether consumers have the adequate information necessary to contextualise and understand the results they receive. Many of the current genetic tests, for example, have been developed based on largely ethnically homogenous datasets, and the resulting screening tests may be less relevant for consumers of other ethnicities. For example, the current screening for BRCA1/BRCA2 by 23andMe would capture 81% of mutations among women of Ashkenazi Jewish ancestry, but would miss nearly 90% of BRCA mutations in the general population (Murphy, 2019[42]). Receiving a negative genetic test in such cases may lure consumers into a false sense of security if they do not understand the caveats around current testing systems.

Table 3.1. Health reports available through 23andMe

Health predisposition report	Ethnic group
Hereditary Amyloidosis (TTR-Related)	African American, West African, Portuguese, Northern Swedish, Japanese, Irish, British descent
G6PD Deficiency	African descent
BRCA1/BRCA 2 (Selected Variables)	Ashkenazi Jewish descent
Age-related macular degeneration	European descent
Alpha-1 Antitrypsin Deficiency	European descent
Celiac disease	European descent
Hereditary Hemochromatosis (HFE-Related)	European descent
Hereditary Thrombophilia	European descent
Parkinson's Disease	European, Ashkenazi Jewish, North African Berber descent
Familial Hypercholesterolemia	European, Lebanese, Old Order Amish descent
MUTYH-Associated Polyposis	Northern European descent
Late-Onset Alzheimer's Disease	Many ethnicities
Type 2 Diabetes	Many ethnicities

Source: 23andMe (2019[43]), "23andMe: How it works", https://www.23andme.com/en-int/howitworks/.

On the other hand, a false positive test result for a serious health condition will likely introduce anxiety to the consumer, and put new demands on the health system as the results of the DTC genetic testing are re-evaluated through more traditional approaches. In a recent study of raw DTC data, some 40% of variants – including variants that indicated a higher risk for Parkinson's disease and Alzheimer's disease – were found to be false positives when further evaluated (Tandy-Connor et al., 2018[44]).

Many genetic testing sites also offer customers the opportunity to screen for health conditions and diseases that can have a significant impact on their lives, but have no cure. Experts have largely discouraged, for example, the development of screening programmes for non-communicable diseases where no effective treatment or cure exists. Without an effective treatment for the underlying disease or condition, such programmes are both expensive to administer for the health system, and can have limited impact on even the quality of life of the people who find out they have a life-altering health condition. Many countries have actively discouraged the development of screening programmes for Alzheimer's disease and other dementias, for example, given the lack of effective treatment options for curing or even slowing the progression of the disease (OECD, 2018[45]). Yet some direct-to-consumer genetic testing websites offer patients the opportunity to be tested for certain genetic markers of Alzheimer's disease. Given that the symptoms of Alzheimer's disease and other dementias do not typically emerge until patients are older in age, patients may receive information about the *possibility* of developing a non-curable condition, decades before any symptoms would actually emerge.

3.3. Using new digital tools effectively requires both health and digital literacy

Offering patients access to online health records alone will not guarantee that these services are used as they are intended to be. Making use of the new digital tools provided by health systems requires that patients have both the adequate health and digital literacy, as well as access to digital technologies, to benefit from these services.

Poor health literacy has far-reaching consequences (Box 3.3). In response, countries have put a strong focus on improving health literacy. A 2017 OECD survey on health literacy indicated that six OECD countries (Austria, Australia, Germany, New Zealand, Portugal, and the United States) have developed standalone national health literacy strategies, while five have prioritised health literacy as part of a broader public health strategy (Moreira, 2018[46]).

A number of countries have developed community-based health literacy programmes that use counselling services to strengthen health literacy among people living with chronic diseases. Counselling has been found to be an effective approach to improving health literacy and positively changing behaviours that contribute to poor health, such as smoking (Cecchini et al., 2010[47]). OECD countries including Finland, France, Ireland and Switzerland have developed self-management courses promoting the self-management of chronic disease based on the programme "*Devenir actor de sa santé"* (Moreira, 2018[46]). In France, community-based counselling services for people living with diabetes are offered through *La Maison du Diabète*, which provide patients with both tailored advice to the patient and general health and nutrition advice that can strengthen the patient's understanding of their condition and inform their ability to manage their own health.

In addition to policies aimed at improving what patients know about their own health, many health literacy strategies have focused on ensuring that the information provided by the health system – including the health workforce – is communicated so that that users of the system can understand it. Health promotion materials and information provided by governments and health systems are frequently drafted using complicated jargon that makes it difficult to fully understand, particularly for people with low health literacy.

Some countries, including Austria, Canada, France Ireland and the United States, have developed resources or guidelines to promote clear, plain-language spoken and written communication between health care professionals and health systems users. In Ireland, for examples, the Health Services Executive (HSE) developed national guidelines on clear communication that are intended to improve communication by health professionals with patients and raise awareness of possible health literacy issues (Moreira, 2018[46]).

Box 3.3. Poor health literacy has both health and financial costs

Numerous studies have highlighted that people with poor health literacy have worse health outcomes and are more likely to use health services inefficiently than people with better health literacy. Poor health literacy has been strongly linked with poorer use of health services, including higher rates of hospitalisation and use of emergency services, lower mammography screening rates, and lower rates of influenza immunisations (Berkman et al., 2011[48]; Moreira, 2018[46]). Lower health literacy has also been demonstrated to affect health outcomes, with people with lower levels of health literacy experiencing higher mortality rates and poorer health at older ages (Berkman et al., 2011[48]; Palumbo et al., 2016[49]). In a meta-analysis looking at the relationship between health literacy and health management, researchers found that patients with higher health literacy had better rates of adherence – on average, 14% higher – across all included studies, compared with patients with lower health literacy (Miller, 2016[50]). Higher health literacy was found to be associated with both higher medication and non-medication adherence (Miller, 2016[50]). People with poor health literacy have been shown to

be more likely to delay or postpone seeking care, and have more trouble finding a health professional, than people with higher levels of health literacy (Berkman et al., 2011[48]; Levy and Janke, 2016[51]).

Poor literacy can drive many poor health behaviours, from delays in seeking medical treatment to poorer medication adherence. Many of these consequences can also have significant financial costs to the health system. Patients with very low health literacy have been found to accrue significantly more health care costs than patients with better health literacy, even after potentially confounding socioeconomic variables have been considered.

In a study of Medicaid patients with very low literacy in the United States, patients with very low literacy skills were found to have health care costs more than three times as high as patients with better literacy skills – USD 10 688 and USD 2 891 per year, respectively (Weiss and Palmer, 2004[52]). Patients with low health literacy have also been found to have higher emergency room costs in the United States, when compared with patients with adequate health literacy (Howard, Gazmararian and Parker, 2005[53]). While most studies of the cost of poor health literacy have been focused on the United States, research from other OECD countries suggests that the health and financial effects of poor health literacy are similar in other countries. In Switzerland, patients with diabetes mellitus and low health literacy have been found to have higher total costs, higher outpatient costs, and more physician visits than patients with higher functional health literacy (Franzen et al., 2013[54]). Patients with low health literacy have also been found to have higher medication costs for diabetes mellitus in Switzerland (Mantwill and Schulz, 2015[55]).

3.3.1. Overall health literacy remains low

The increasing proportion of people looking to access health information online suggests that patients increasingly seek to take charge of their own health. Between 2008 and 2017, the proportion of people in the European Union who reported searching for health-related information online rose from less than one in three to more than half of adults aged 17-74. Across the OECD, adults reported that health information-seeking was the second most common online activity (Moreira, 2018[46]).

The growth in people searching for health information online has not been matched by a rise in overall health literacy . More than half of people in most OECD countries are considered to have a poor level of health literacy (Moreira, 2018[46]).

New digital tools offer a growing number of opportunities for patients to more easily obtain health information, but the quality of this new material raises serious questions about the ability of new digital sources of information to deliver information that can truly improve health literacy. Repeated reviews of health information available online and through social media sources ("Web 2.0") have consistently demonstrated that most online health information is of low or variable quality (Zhang, Sun and Xie, 2015[56]). Yet the seemingly exponential increase in information has not been accompanied by a similar scale-up of how this new material should be interpreted. Patients are left with a limited capacity to process the new information they can so easily access.

People with low health literacy, moreover, have been found to not accurately evaluate the health information they find online (Diviani et al., 2015[57]). This suggests that at times, the effects of poor health literacy may even be aggravated, not mitigated, by the use of online health resources.

An emerging digital divide reflects existing inequalities

In part, because the scale of up patient-facing health technologies has occurred outside of the traditional health system, available digital tools will not necessarily correspond to the most pressing health needs of the population. Moreover, current patterns of health-seeking behaviour suggest that a new digital divide in health information will likely exacerbate existing health inequalities.

Even as overall access to the internet has grown, inequalities in the use of new technologies for health have persisted, most notably by two factors that play a significant role in health as well as health care utilisation: age and income. Adults in the highest income quartile, meanwhile, are 50% more likely to use the internet to research health information, compared with adults in the lowest income quartile (OECD preliminary analysis).

The association between higher income and socioeconomic status and better health has been repeatedly demonstrated (OECD, 2017[58]). People with higher incomes have been found to have higher life expectancies as well as better health throughout their lives compared with those at a lower level income across OECD countries (OECD, 2017[58]). This means that the populations who stand to gain the most from better literacy are the least likely to benefit from it – an outcome strongly at odds with the prevailing view that digital technology will ipso facto promote health equity and even out power asymmetries in the sector.

Across the OECD, the proportion of young adults (16-24) using the internet is 43% higher than older populations. This digital divide extends to the use of online tools for health. Recent data suggests that the proportion of people who use the internet to search for health information is five times higher than among young adults (16-24) than it is among people 75 and over (OECD preliminary analysis).

Emerging evidence further suggests that much of the high-quality health information available online, such as health information available on government websites, is written at a reading level higher than that of many people with low health literacy. A study of available diabetes information online found that people with low health literacy ended searches earlier and were less likely to get the same benefit from available information, as compared with people with higher levels of health literacy (Yom-Tov et al., 2016[59]). People with low health literacy have been found to be less likely to use computers and the internet to search for health information, and to spend more time on less-important information when they do use digital tools (Kim and Xie, 2017[60]).

3.3.2. The digital divide risks exacerbating instead of reducing inequalities

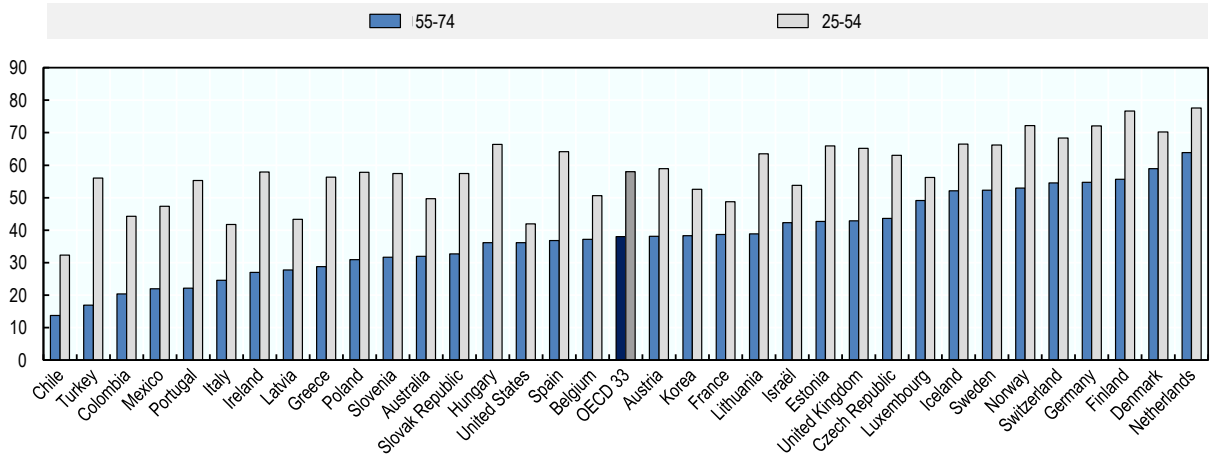
The internet's rapid rise has meant that across many sectors some people and population groups have struggled to keep up with the digital disruption that has quickly transformed many sectors. Health care is no exception.

Across 33 OECD countries, older adults ages 55-74 in every country are less likely to report recently using the internet for health information, compared with younger adults (Figure 3.3). Adults 25-54 are 50% more likely to report using the internet to find health information than older adults, with 39% of people 55-74 having used the internet for health information in the previous three months, compared to 59% of people 25-54.

Adults with lower levels of education are less likely to report looking for health information online when compared with higher educated adults in the same country. Across 33 OECD countries, individuals aged 16-74 with no or low educational attainment were only half as likely to have reported searching for health information online over the previous three months, compared with those with high educational attainment. Just 34% of individuals with low educational attainment reported having looked for health information online, compared with slightly over half (53%) of those with medium educational attainment, and more than two in three (68%) people with a high level of education (Figure 3.4).

Figure 3.3. Older people are less likely to seek out information online

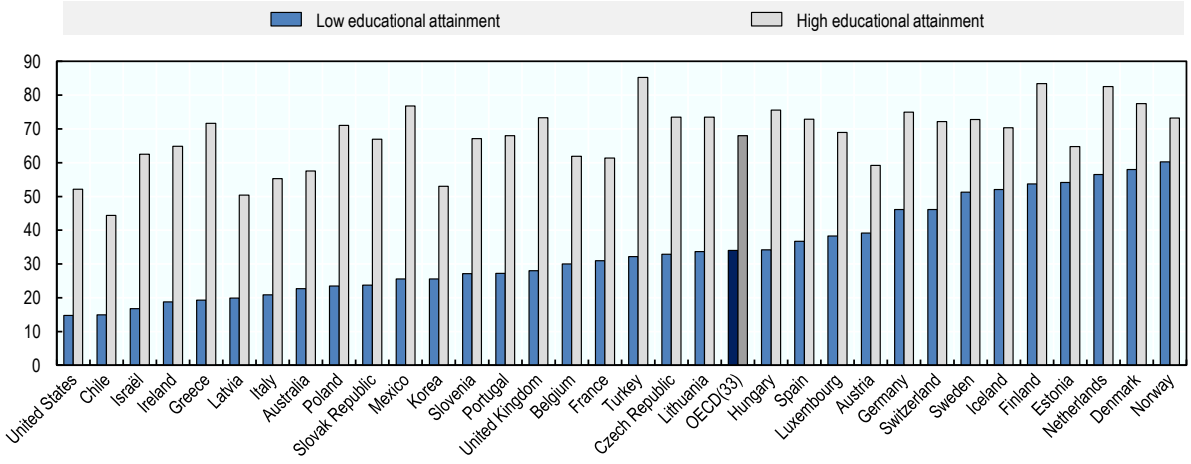
Percentage of individuals using the internet for seeking health information in last three months by age, 2018 (or most recent)



Note: Data for Chile, Colombia, Israel, and Switzerland refer to 2017. Data for Australia refers to 2016. Data for the United States refers to 2015. Colombia was not included in the OECD average as it is still officially in the accession process.
Source: OECD ICT Access and Usage by Households and Individuals Statistical Database 2019.

Figure 3.4. Education level can influence seeking information on line

Percentage of Individuals using the internet for seeking health information in last three months, by educational attainment 2018 (or nearest)



Note: Data for Chile, Israel, and Switzerland refer to 2017. Data for Australia refer to 2016. Data for the United States refer to 2015.
Source: OECD ICT Access and Usage by Households and Individuals Statistical Database 2019.

3.4. Health systems need to prepare for the rise of the 'informed patient'

People-centred care is often invoked as a solution to many problems with few risks. But better health literacy and empowerment of patients to engage in their care through digital technology can also increase demands on the health system. Should the effects of digital literacy continue to accrue unevenly – with younger, more educated, and wealthier patients most actively engaged – the resulting increase in health-

seeking activity will be unlikely to generate commensurate health benefits, nor meet social policy objectives. It will instead represent an inefficient allocation of resources. Moreover, digital technology's broader, inherent tendency to fragment populations into isolated, individual 'users' exacerbates the need for governments to address tensions between the interests of the informed individual patient and the interests of populations.

3.4.1. Patient empowerment can promote inefficient use of health system resources

Examples from the recent proliferation of software as medical devices (SaMD) illustrate this challenge. Cardiologists have raised concerns, for example, over an anticipated increase in demands on heart specialists following the launch of the most recent Apple Watch, which contains a monitor to detect atrial fibrillation. Given the demographic groups who purchase Apple Watches, the anticipated low prevalence of atrial fibrillation in the population and the consequent high false positive rate raise questions about the balance between costs incurred in the health system (visits to specialists, further tests) compared with the small likelihood of benefit (detecting true cases before they result in further complications). Such tools arguably act as unofficial screening programmes for low risk populations, organised outside the health system, that nevertheless imply real costs to the system itself.

Similar concerns have been raised over demands stemming from the rapid increase in DTC genetic testing in recent years. In the United States, recent studies indicate that 20-30% of consumers consult health care providers after they undergo DTC genetic testing (Moscarello et al., 2018[61]; Wang et al., 2018[62]). In many of these cases, demands on the health system may even go beyond a physician consultation to include additional screening and other tests, particularly where the DTC genetic testing suggest the consumer may be at higher risk for a previously undetected health condition (Moscarello et al., 2018[61]).

In recent years, for example, there has been a dramatic rise in the number of contralateral prophylactic mastectomies (CPM) performed on women, particularly among younger women with breast cancer. This increase is believed to be partly driven by the preferences of women undergoing a preventive mastectomy, who believe – despite no clinical evidence supporting this belief – that a double mastectomy will increase their likelihood of survival (Rosenberg et al., 2013[63]).

Traditionally, many OECD countries have offered women at higher risk of developing breast cancer – for example, women with a family history of breast cancer – the opportunity to screen for BRCA gene mutations. In most cases, genetic testing for BRCA has not been allowed outside of medical establishments. With the availability of DTC testing, a much broader population who would not previously been eligible for or aware of screening for BRCA can now receive their results. Current research underscores both the possible limitations of DTC screening, and the possibility of false positive results. While in some cases, screening through DTC will certainly catch cases that would otherwise have been missed, it may also result in increased demands for interventions that would otherwise have been delayed or never happened at all. When combined with insufficiently informed patient preferences – such as demands for prophylactic double mastectomies – the implications for both the individual and the health system could be significant.

A better informed patient population may also introduce inefficient demands on the health system based on the widening disparities in how more and less privileged health systems users seek out and engage with new sources of information. Surveys of DTC genetic testing users, for example, indicate that the populations seeking out genetic health information through such tests are overwhelmingly highly educated, of very high income, and of the dominant ethnic group in the country. In the United States, for example, a survey of 23andMe and Pathway Genomics users found that 91% of customers were white, 80% had at least a college degree, and 43% had an income of USD 100 000 or more (Koeller et al., 2017[64]).

There is growing evidence to suggest that without well-designed public policies, younger, healthier, more technology-savvy patients may make use of new digital options within the health system in ways that can

introduce new inefficiencies to the health system. In the United Kingdom, the introduction of *GP at hand*, an app-based primary care service, has been adopted disproportionately by patients who are younger, more educated, and wealthier: 94% of *GP at hand* patients, for example, are younger than 45 (Burki, 2019[65]). In theory, shifting healthier patients to online health services could help to free up the limited resources of primary care for patients with greater need. At the same time, patients of *GP at hand* were found to use the service more frequently than a similar demographic accesses traditional primary care services, suggesting that the convenience of the mobile services may have introduced "supply-induced demand" (Burki, 2019[65]), although it isn't known if the additional use met genuine health need or not. The demographic profile of *GP at hand* users also indicates that any shift towards a digital approach to health services must be undertaken with a strategy to address the digital divide in mind.

3.4.2. Public and individual interests need reconciling

The interests of the patient may not always be aligned with broader social welfare. As patients become more informed and engaged, their preferences may shift in ways that can be detrimental to the broader health system, yet wholly rational from the patient perspective. These preference shifts can be exacerbated by the spread of (mis)information over new methods of communication, including social media. Views held by a small but vocal group can now be shared within and beyond local geographies and exercise disproportionate influence and power in public debates.

In recent years, for example, vaccination rates have dropped significantly in certain communities in North America and European countries. Substandard vaccine compliance has been linked to a rise in the number of measles outbreaks across parts of the United States, Canada and Europe that have led to many deaths and sparked serious discussion about the dramatic rise in vaccine scepticism in recent years. Paradoxically, vaccine hesitancy and refusal has in this case been driven by resistance among parents with high socioeconomic status and good health literacy. The rapid spread of vaccine scepticism across similar communities in countries around the world has been driven in large part by the ability of people to engage with and share misinformation that would previously have been difficult to widely disseminate. It is widely believed that the origin of the current rash of vaccine scepticism, for example, can be traced to a withdrawn study linking the measles, mumps, rubella (MMR) vaccine to an increased risk of developing autism. Published in the Lancet in 1999, the study has since been withdrawn and the lead author largely disgraced. Yet the widespread consensus shared by the medical, research, pharmaceutical, and policy establishment has paradoxically served to strengthen detractors, who have pointed to attempts to minimise the damage done by the article, and present strong evidence refuting its findings, as proof of conspiracy which validates the disgraced report (Iacobucci, 2019[66]; Royal Society for Public Health, 2018[67]).

The most effective response enacted by governments so far – mandating vaccinations for school-age children – arguably runs counter to the ethos of a person-centred health system responsive to the preferences of the patient.

3.5. New approaches are needed to promote and govern digital tools for patient engagement

The risks illustrated above should not diminish the enormous potential of developing a better-informed, engaged patient population. But they do highlight the importance of ensuring that governments create a policy environment that promotes a system of enabling success, where the challenges and unintended consequences of digital technologies are also anticipated and responded to. Governments and health systems face a complex challenge: they must support and facilitate health and digital literacy and enable patient empowerment in the health system, while also developing effective strategies to that anticipate possible challenges that could arise from more assertive and empowered patients.

3.5.1. Promoting the constructive use of digital technologies

One of the major challenges arising from the rapid increase in the amount of information available to health systems users today is the ability for them to effectively identify what constitutes quality information and tools. Encouraging health systems users to choose high-quality, informed resources can be challenging when alternative sources of information are more widespread or heavily promoted. Continued support to strengthen health and digital literacy, particularly among marginalised, underprivileged, or older communities, will be critical to ensuring digital technologies are used for positive transformation.

Strengthening the capacity of health systems users to harness the benefits of new digital technologies is also critical. Health systems offer a wealth of user-oriented information and resources, and it is important that these resources are accessible. Health systems users must be involved in the development of user-oriented materials, including the design of electronic health records, and it is important that information is delivered in a clear communication style that reflects the health and broader literacy of the population. Health systems users must be made aware of new data sources – such as patient portals – including through awareness campaigns. Bringing the health workforce on board is also critical in encouraging the uptake of new resources by health systems users.

3.5.2. Governance and regulatory mechanisms need to be updated

In addition to building capacity of patients and the public, approaches to governance of patient-oriented technologies are needed. Given the speed at which new technologies are developed, deployed, and modified, traditional approaches to clinical approval may not be appropriate. Developing a transparent approval process would create an important signal of trust, helping direct patients towards higher-quality information in a saturated marketplace.

Efforts to develop guidance around these new tools are underway, including a recent pilot programme between technology companies and the Food and Drug Administration in the United States (U.S. Food & Drug Administration, 2017[68]). Governments must also strengthen digital literacy efforts, including beyond the health system, to ensure that benefits are shared across the population and not concentrated among the wealthiest and healthiest.

3.6. Conclusion

The emergence of new digital technologies and tools offers an unprecedented opportunity for individuals to inform themselves and actively participate in decisions affecting their own health. Nearly all OECD countries have moved towards promoting tools intended to inform patients about their own health.

However, many people in OECD countries continue to have poor digital and health literacy. Strengthening the capacity of people to take full advantage of health information and new digital technologies will become ever more important as the digital transformation – of both health care and society more broadly – continues. Countries must continue to promote health and digital literacy policies that enable populations to take full advantage of the new digital tools available both within and outside the health sector. Careful planning, using good data, is needed to ensure that the shift towards greater use of patient-oriented digital technologies does not widen health disparities.

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Notes

[1] Australia, Canada, Estonia, Israel, Latvia, Lithuania, Luxembourg, Netherlands, Norway, Poland, Slovenia and Switzerland.

[2] See also Chapters 2 and 4 for further discussion on user-based design.

4 Engaging and transforming the health workforce

Karolina Socha-Dietrich

Digital transformation, which includes the generation of electronic health data as well as its appropriate use, bears the promise to help address the increasing demand for health services by improving the effectiveness and productivity of health service delivery. This chapter discusses how the health workforce matters for a successful implementation of digital technologies in general and for making the best use of data collected across a health system in particular. It also discusses how the deployment of various digital innovations can affect the health professionals, for example, in terms of their roles and the way their daily tasks are carried out. The chapter describes also the skills needed to best put health data to work as well as examples of national approaches to ensure an adequate supply of these skills, to appropriately engage health workers, and build their trust in the digital technologies.

4.1. Introduction

One of every ten jobs in OECD countries is in health and social care, placing the sector among the largest employers. Productivity improvements have been hard to achieve in this sector but are increasingly needed in the face of evolving health needs on the one hand and limited resources on the other. Digitalisation in general – which includes the generation of electronic health data as well as its appropriate use – bears the promise to help address the increasing demand for health services by improving the effectiveness and productivity of health service delivery.

So far, in the majority of the OECD countries, the most prevalent instance of the use of information technology in the health sector has been the introduction of electronic health records (EHRs), although their implementation has not always been entirely successful. More recently, in some countries, the health sector has started to make use of digital technology to analyse the data generated in the sector to, for example, better adapt services to the people's health needs and preferences, to improve patient involvement, as well as to advance the communication and cooperation among health professionals to better integrate care.[1]

Emerging digital tools based on Big Data and developments in artificial intelligence (AI) – notably, deep learning – also offer a promise of customised decision support for clinicians and creating "learning health systems", in which knowledge contained in the diagnoses and decisions made by nearly all clinicians and the respective patient outcomes inform the care of each individual patient.

This strategic orientation to harness health data requires not only investing in the infrastructure and interoperability, but also the sustained engagement of health workers, who as front-line users of the technology need support in building the capacity to put it to work effectively and safely. Far too often, however, the potential benefits of digital technologies cannot be fully realised because health professionals are not adequately skilled for using them, or the day-to-day work processes are not adequately re-engineered to enable the technology to add value. Moreover, health workers are rarely involved in the development of digital tools meant to assist them, which frequently results in a suboptimal design that does not address their (and their patients') needs adequately. All of this reveals a troubling picture of health workers facing a serious misalignment of skills or jobs and tools at their disposal, which is not only likely to result in inefficiency and waste, but also places undue burden and strain on the workers.

Furthermore, the stakes are decisively higher when a decision or recommendation provided by automated systems affects health outcomes rather than travel arrangements, the shipping of products, or the selection of a car insurance policy. While data-driven digital innovations continue to be designed in order to change the practice of health care, the existing professional and ethical frameworks do not necessarily account for these developments. As a result, health workers face unanswered questions of ethical and legal nature, for example, about their and the automated systems' respective roles, how to ensure that automated systems do not crowd out patient-provider shared decision making, or about the implications for accountability of actions based on AI-produced information.

Against this background, this chapter discusses how the health workforce matters for a successful implementation of digital technologies in general and for making the best use of data collected across a health system in particular. It also discusses how the deployment of various digital innovations can affect the health professionals, for example, in terms of their roles and the way their daily tasks are carried out. The chapter describes also the skills needed to best put health data to work as well as examples of national approaches to ensure an adequate supply of these skills, to appropriately engage health workers, and build their trust in the digital technologies.

4.2. Together, humans and machines can generate better health outcomes than either could alone

The range and volume of data – including clinical, genetic, behavioural, and environmental data – collected within health systems is growing rapidly, in part because much of it is produced directly in digital form. Every day, health professionals, biomedical researchers, and patients produce vast amounts of digital data through the use of, for example, EHRs, genome sequencing machines, high-resolution medical imaging, smartphone applications, and Internet-of-Things (IoT) devices that monitor individuals' health (OECD, 2015[1]).

As discussed in Chapter 2, solutions harnessing health data and digital technologies – such as data-driven risk-stratification models, clinical decision aids, tele-monitoring of the patients' health, or technology-assisted provider networks and communications infrastructures – provide an opportunity to improve the access, effectiveness, and productivity in health services delivery. If leveraged adequately, data available within health systems help, for example, to reduce errors, to improve the co-ordination of care, or to better identify specific health needs of individuals and population groups. It can enhance the precision in targeting preventive interventions at the persons most likely to benefit from them, while avoiding treating others unnecessarily, and provide tailored care pathways to the growing number of people living with chronic conditions, thus reducing the risk of hospital (re)admissions (see Chapter 2 for further discussion).

Moreover, emerging digital tools based on Big Data analytics and the recent developments in AI – notably, deep learning – allow machines to perform cognition(-like) functions. For many jobs, these developments fuelled the question: "*Can the tasks of this job be sufficiently specified, conditional on the availability of big data, to be performed by state of the art computer-controlled equipment?*" (Frey and Osborne, 2017[2]). OECD expects that the technology is likely to affect nearly half of all jobs in terms of their task composition, with one in seven jobs having high probability of being entirely restructured in terms of job tasks or significantly downsized (Nedelkoska and Quintini, 2018[3]). These estimates refer to technological possibilities, abstracting from the speed of diffusion and likelihood of adoption of such technologies.

4.2.1. Most health sector jobs will remain, but some specific tasks will become automated, freeing up time for more complex activities

The health-sector workforce comprises a high proportion of professional jobs. The execution of these jobs requires complex human interactions, similar to the jobs in education, for example. Compared to the entire labour market, health sector jobs are therefore among the least likely to be automated according to the latest estimates by the OECD (Nedelkoska and Quintini, 2018[3]) (Figure 4.1).[2]

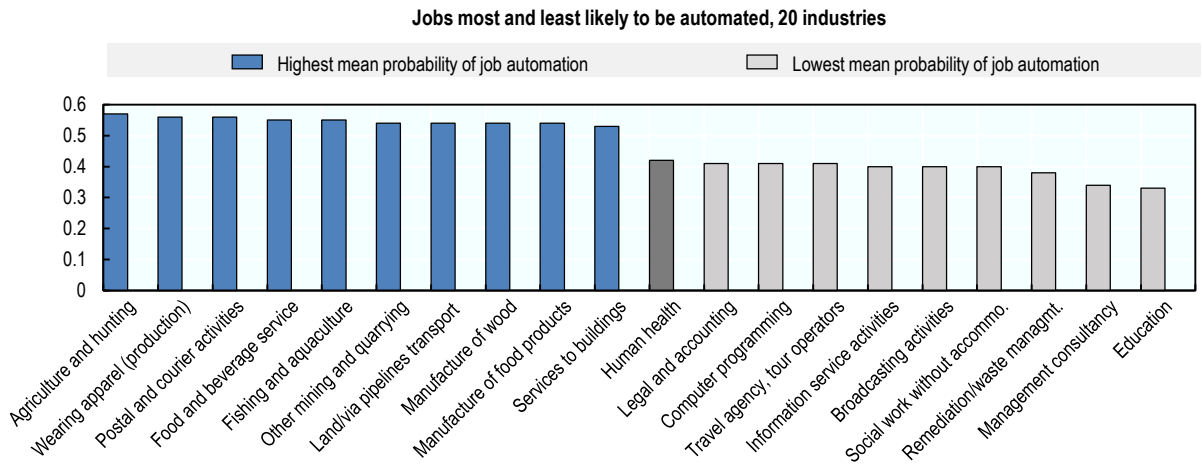
However, many health workers could see a significant change in the way their jobs are carried out. Machines are likely to complement health workers in tasks that are repetitive, time-consuming, and heavy on data processing, such as selecting irregular results from large volumes of preventive or routine chronic care tests, synthesising information relevant for a given patient's condition from numerous sources (patient records, archives, guidelines, specialist recommendations), or analysing patterns in patient outcomes for predicting behaviour (for example, no-shows), and informing regular improvements in practice. In short, in the health sector the augmentation of human labour is more likely than its automation (Davenport and Glover, 2018[4]; Health Education England, 2019a[5]; Nedelkoska and Quintini, 2018[3]; Confédération suisse, 2017[6]) – (Box 4.1).

The resulting gains in productivity and effectiveness could make it possible to redirect staff to address service bottlenecks; to allow greater interaction with the patients to address their needs more effectively, efficiently, and equitably; as well as to provide time for engaging in value-added tasks that require critical thinking and creativity, such as quality improvement.

However, in order to take advantage of these opportunities, the health workers must trust and be equipped with the mindset and skills to use digital tools effectively and safely. Realising the full potential of health

data and digital technologies requires also more health data scientists, more technologists with an understanding of the health sector, and more clinical leaders with an understanding of technology to ensure the right combination of digital skills, an ability to improve processes, and an ability to design solutions that truly benefit patients and health workers.

Figure 4.1. Health jobs are among the least likely to be automated



Notes: Not all tasks related to caring for and assisting patients that cannot be automated could be included in the calculation; hence, estimates for the health sector are biased upwards. High mean probability of job automation means that the mean job in a given industry is highly automatable based on tasks it involves. Low mean probability of job automation indicates that the mean job in a given industry might change with regards to how some of its tasks are carried out.
Source: OECD (2018) "Automation, skills use and training", Paris, https://doi.org/10.1787/2e2f4eea-en; OECD Survey of Adult Skills (PIAAC) 2012, 2015.

Box 4.1. Augmentation of human labour is more likely than automation – the case of radiology

Since many decades, making use of the steady increase in available computing power together with qualitative developments in digital technologies continues augmenting profoundly the work of health care professionals.

Take X-ray imaging, for the sake of concreteness. It and its medical use started out at the end of the 19th century, taking two-dimensional analogue pictures. Today, digital sensors akin to the CCD chips that took the place of the film in digital cameras produce radiographs directly in digital form; apart from permitting for a dose reduction benefitting the patient, this admits the direct use of image enhancing techniques and fast, lossless duplication and transfer.

Next, the rise in computing power made possible the necessary computations for reconstructing three-dimensional (tomographic) images – also used in MRI, which does not use ionising radiation. Today, contingent on the ever increasing locally available computing power, medical images can be taken in four-dimensions, i.e. processes and movements can be followed over time. The automatic differentiation of tissue types and many other image processing techniques are commercially available features.

Alongside this technical progress the medical specialisation of radiologist developed, who specialises in understanding medical imagery (particularly also the limitations) and in interpreting it. Radiology is a growing branch of medicine in the number of images taken, in revenue, and in people employed. In fact, in many countries there is a shortage of radiologists. For instance, a number of OECD countries expect most profound capacity challenges in the radiology workforce as many consultant posts remain

unfilled (The Lancet, 2016[7]). This is in spite of the fact that there are plenty of medical doctors who combine another specialisation, e.g. as surgeon, orthopaedician, or gynaecologist, with a specialisation in radiology. These shortages will exacerbate in an aging population.

The increase in computer power also made it feasible to analyse large datasets containing medical imagery using artificial intelligence (AI), especially deep learning. AI had some astounding successes, outperforming humans and non-AI computerised data analyses in pattern recognition, data segmentation, image classification, and other tasks – outside and within medicine research – but it is really not understood why. Neither is it understood why AI sometimes fails spectacularly when facing setting modifications that are irrelevant for a human observer. Generally, computers need 'kind' – as opposed to 'wicked' – learning environments (Hogarth, Lejarraga and Soyer, 2015[8]) to succeed. In a 'kind' learning environment accurate inference is made possible by a close and accurate feedback on predictions (or actions taken in general) as well as small or no variation between the dataset used for learning (training) and the one to be analysed. If the learning environment is not kind enough, successful learning requires much larger training datasets, but might become altogether impossible in the presence of biases. Medicine is by default poised by uncertainty as well as, oftentimes, unavoidable biases and as such represents a 'wicked' learning environment; potentially, with the exception of some clearly delineated data-rich subsectors. As a consequence, blindly relying on AI outputs in the vital setting of the health care sector is not an option, at least not for some time to come.

The aforesaid recommends such computer algorithms for well defined – i.e. 'kind' – sub-problems involving the processing of big amounts of data as input to a human-led medical examination and to a – thus better informed – human-led decision making. In medicine this person will be a highly trained professional, who, additionally, learned how to make the most of the strength of the computer and who will be needed to train the computer initially as well as repeatedly if there occur changes in data acquisition – for example, when improved equipment becomes available – or reference standards – for example, due to progress in medical research. A captivating example outside the health-sector context for the achievement potential of such human-computer tandems is Advanced Chess, where unranked human chess players in cooperation with strong PCs can outperform grand masters and supercomputers (Epstein, 2019[9]).

It follows that the need for large training datasets bars computers from permeating areas with sparse data. For example, for relatively rare patients like those in the highest age groups or rare diseases large enough datasets will never exist; but even where large datasets could be available in principle, they must first be created, analysed, and labelled (by diagnosis) by highly trained specialists. Humans, in comparison, can learn how to interpret less homogeneous imagery based on theory – combining concepts from different scientific fields (e.g., anatomy, physiology, or medical physics) – even on small samples.

As an aside, all of the above makes speculating about the demise of the radiologist due to the advent of AI – as has happened in the media – appear exaggerated, even in the unrealistically narrowed down sense of a pure diagnostician, which denies them their roles as, inter alia, therapists and researchers. In addition, their expertise will be needed for continued development and refinement of AI in this field.

Finally, the models of health service delivery are continuously changing in attempts to increase the efficiency and effectiveness of care. This potential for improvement means that as routine and repetitive tasks are automated humans can dedicate more time to non-standard tasks requiring critical thinking, adaptive problem solving, and creativity. Even the much less complex technology – such as automated drug dispensing in hospitals – have not led to the demise of hospital pharmacists. Rather, the technology opened the opportunity for pharmacists to engage in, for example, strategic procurement of hospital pharmaceuticals – a function which was previously performed like an administrative task by personnel without pharmaceutical expertise or insights into patient care. The latter are crucial for the transition to strategic value-based procurement, though.

4.3. Engaging and transforming the health workforce is essential

Starting in the 1950s, multiple industries – financial services, retail, entertainment, and others – have invested in digitalisation and leveraging digital data with the aim to transform and improve their business models. While ultimately successful, these industries experienced a number of intermediate failures. Each of these failures has its own particulars, but all share certain overarching characteristics:

- the failure to engage and gain the buy-in of end users of the new systems;
- the failure to invest in adopting the skill mix of the end users of the new systems, or to create new roles for individuals with the appropriate skills to manage the change;
- the failure to appreciate the changes to the nature of the work, the tasks to be done, and who does them (The National Advisory Group on Health Information Technology in England, 2016[10]).

In the labour intensive health sector, any effort to improve the service delivery through digitalisation and the use of digital data also requires the initial and sustained engagement of the people doing the work. Moreover, there is a need to ensure that health workers are adequately supported through education and training to effectively and safely adopt the new and emerging digital work tools. Without the right people and skills, digitisation will fail, or at least not achieve its full potential. Finally, in order to avoid simply digitising ineffective and inefficient analogue processes, digitisation needs to be accompanied by rethinking the work processes; in particular, the affected tasks should be reimagined for a digital environment.

4.3.1. Adoption of digital data systems shifts the mix of skills required in health-sector jobs

As automation and digital technologies integrate into health services, the mix of skills required in health-sector jobs shifts. Some OECD countries – for example, Australia, Norway, Switzerland, New Zealand, and the United Kingdom – completed a review or established a regular process to assess how technological and other developments (for example, IT, AI, genomics, or demographics) are likely to change the skill requirements as well as the roles and functions of health workers over the next one to two decades, including the consequences for the education of future and the training of current health workers. A similar review is underway in Canada, with results to be published in 2020.

In general, the successful implementation requires

- a (larger) cadre of **clinician-leaders in digital and information technology** with a combined understanding of clinical practice, technology, and change management. These individuals are needed to ensure that digital solutions do work for the benefit of patients and the front-line health workers as well as to serve as crucial bridges between the technology and the front-line staff.
- **clinician and non-clinician informatics professionals**, researchers, programme evaluators, and system optimisers with expertise in clinical informatics. Among other skills, such individuals must possess a strong understanding of user-centred design principles and understand the critical role of patients and workers in adopting innovation throughout health and social care organisations.
- every front-line clinician to possess a **foundational level of digital skills** such as a basic understanding of how the data employed by digital tools is collected, analysed, and how the algorithms powering the digital tools use the data to produce information. These skills should not be tied to any specific technology but allow every clinician to exploit digital tools and data to improve care and fully partner with patients, as well as help them understand and tackle the underlying biases and challenges in the data.

A clinician-leader in information technology (often referred to as chief clinical information officer) is an emerging role in health systems globally. While responsibilities of the role and the scope of practice vary across health systems, a clinician-leader in IT requires competencies in both information technology and

leadership, but first and foremost they must be clinical professionals with front line experience of patient care. Their clinical background may be medicine, nursing, or pharmacy, depending on the needs. A cadre of clinician-leaders in IT is essential to ensure the new technology addresses the needs of patients and health professionals, to build trust in technologies among and engage with the wider health workforce, and to manage the culture change needed to drive learning across organisations (The National Advisory Group on Health Information Technology in England, 2016[10]; Sood and Keogh, 2017[11]).

The clinician-leaders in IT will need to be supported by teams of both clinician and non-clinician informaticians as well as researchers, programme evaluators, and system optimisers with expertise in clinical informatics. These people shape the information that is communicated to and used by the front-line health workers; hence, they should possess a strong understanding of user-centred design, among other skills (The National Advisory Group on Health Information Technology in England, 2016[10]).

Most importantly, the majority of front-line health workers, clinicians in particular, will require some element of digital skills to effectively and safely navigate a data-rich health care environment. The skills requirements might vary depending on their respective role and/or specialty, but a basic understanding of how the data employed by digital tools is collected, analysed, and used to produce information will be most essential, among other things, for the critical appraisal and interpretation of the information as well as for providing patients with an explanation of the information or outcome produced by an automated system. Furthermore, health workers will require training in the ethics of autonomous systems/tools and AI to be able to address any related ethical or patient safety considerations.

As the adoption of digital tools aims to support the transition towards value-based and personalised models of care, the investment in developing digital skills needs to be complemented by strengthening the skills in person-centred communication and patient-provider shared decision making. A successful transition towards value-based and personalised models of care will require that care and treatment decisions become a collaborative process between a person who seeks help (or their family and/or carers) and the providers, taking into account the best scientific evidence available as well as the person's individual and social context, values, goals, and preferences (Kon et al., 2016[12]). This necessitates, for example, understanding what really matters to patients in terms of health outcomes. Therefore, effective people-centred – as opposed to disease-centred – communication on the part of the health professionals, together with the ability to engage a person who seeks care through shared decision making, are crucial.

In the context of people-centred care, socio-cultural competencies also matter, as they are essential for an effective communication between people belonging to different social, cultural, or age groups. Moreover, shifting the focus from a disease to a whole-person and ensuring the delivery of seamless care requires strong socio-emotional skills to work collaboratively and flexibly across disciplines and provider organisations (OECD, 2018[13]).

4.3.2. The necessary skills needed are often in short supply

As mentioned earlier, complementary investment in workers' skills and work-processes redesign are needed to successfully deploy technology and deliver promised gains in productivity and performance. There is, however, growing evidence of skills shortages, including digital skills, among health workers. An OECD study (2016[14]) reported on the results from the 2011/2012 OECD Programme for the International Assessment of Adult Competencies (PIAAC), which revealed the overall extent of the skills mismatch among nurses and doctors in OECD countries; in particular 51% of doctors and 46% of nurses reported under-skilling for their daily jobs. While this international study does not contain information on in which of their day-to-day tasks doctors and nurses feel sub-optimally prepared, numerous other publications provide indications of digital skills shortages among front-line health professionals (OECD, 2018[13]; The Lancet Global Health Commission, 2018[15]; Swiss eHealth Forums, 2017[16]).

Digital technology has already changed the way that health care professionals practice and, while many of them see the potential that these changes can bring to improving the quality and cost-effectiveness of health care, many are also frustrated (Payne et al., 2015[17]) or are struggling to adapt because they do not know enough about the underlying information science in these new digital tools and systems (Fridsma, 2018[18]).

Depending on the concrete study perused and varying between professional categories, between 30 and 70% of health workers report not to have all the skills they need to use digital technologies and fully engage with digital information (Hegney et al., 2007[19]; Foster and Bryce, 2009[20]; Skills for Health, 2012[21]; European Commission, 2013[22]; European Health Parliament, 2016[23]; Quaglio et al., 2016[24]; Melchiorre et al., 2018[25]). However, these studies are based on small samples of health professionals and/or focus on narrowly defined skills, such as the ability to operate a digital tool, while the ability to understand and tackle inherent data limitations or risks such as automation bias (favouring suggestions made by automated systems and ignoring other sources of information) remain largely unassessed.

Need for tailored training curricula and leadership

The shortage of digital skills is also reflected in the 2019 Manifesto of the European Medical Students Association (EMSA), in which medical students have called for actions to be taken by European Institutions after the 2019 European Parliament elections to tackle Europe's health challenges. Among the six priority calls for action, EMSA has included a call to put training and education in digital health on the policy agenda and enhance the awareness and trust in digital technologies. More specifically, EMSA calls for the inclusion of educational formats on digital health in medical curricula and for the creation of platforms for faculties to exchange information about best practices in digital health education (EMSA, 2019[26]). While digital health might feature in health professional education programmes and training, it is not always taught at a high enough level as revealed by the gap analysis undertaken within the 2016-2018 *EU-US eHealth Work Project*, which has had the overall goal of mapping, quantifying, and projecting the need, supply and demand for digital workforce skills and competences in the European Union (EU) countries, United States, as well as a number of developing countries (EU*US eHealth Work Project, 2019[27]).

Furthermore, in most OECD countries, health systems lack clinician-leaders with the necessary skills in health care improvement and the redesign of care enabled by digital technologies (The National Advisory Group on Health Information Technology in England, 2016[10]). There is also evidence of a deficit of both clinician and non-clinician informatics professionals (Burning Glass - Career in Focus, 2014[28]; The National Advisory Group on Health Information Technology in England, 2016[10]). In the United Kingdom, for example, the chief clinical information officers (CCIO) Network undertook a survey of its members in 2016, in which 76% of respondents disagreed or strongly disagreed with the statement, "*We have enough trained clinicians in health IT and informatics to maximise the potential of our systems*" (The National Advisory Group on Health Information Technology in England, 2016[10]). In the United States, there are reports of shortages of health informatics workers who can meet the modern requirements of managing medical information – the new and emerging health informatics positions (such as Clinical Analyst) stay open twice as long as the ones they are replacing (such as Medical Records Clerks) (Burning Glass - Career in Focus, 2014[28]).

One possible explanation is that technology is changing the field very rapidly; hence, some of these hard-to-fill positions are examples of jobs recently created by new technology. Another contributing factor is, however, that many of these new jobs are hybrids, requiring skill sets from different disciplines, such as nursing and IT, which are not typically taught together (Burning Glass - Career in Focus, 2014[28]).

Skills supply and demand need to be considered simultaneously

Without the availability of full-time jobs with a sustainable career track, few talented individuals will choose to leave the practice of clinical medicine, nursing, or pharmacy to obtain additional training and certification

in health information technology. Similarly, even if suitable education programmes combining knowledge of clinical practice with IT expertise are offered, few students will choose this hybrid path as a career choice when these jobs are not recognised as central to health service delivery, and hence, the corresponding positions are in shortage although they would be needed for a functioning health system (Health Education England, 2019a[5]; The National Advisory Group on Health Information Technology in England, 2016[10]).

4.3.3. Technology must not 'get in the way' of work

In the majority of the OECD countries, the introduction of EHRs has been the most significant manifestation of digital technology in the health sector over the past two decades. However, EHR implementation has not always been entirely successful. While these initiatives helped create an important and powerful infrastructure, they have not always been fully informed by, and designed with the needs of patients and health professionals in mind.

A widely held criticism of many EHR platforms is their relative inattention to basic principles of user-centred design (usability), particularly when judged against the electronic tools commonly used in the general population. In the health sector, usability is the extent to which the technology can be used efficiently, effectively, and satisfactorily based on system design, as well as how it is customised in a given work environment to the specific workflows that health professionals employ (International Organization for Standardization, 2010[29]).

Indeed, in some countries, EHRs were designed to address billing and financial functions at least as much as, if not more, than the clinical needs of patients and clinicians (Watcher, 2015[30]). In other cases, suppliers have not put in the resources to perform adequate testing with actual users (The National Advisory Group on Health Information Technology in England, 2016[10]). An international review of literature on electronic-medical-record (EMR) and related electronic-health-record (EHR) interface usability issues revealed EMR and EHR usability to be hampered by, for example, problems with control consistency, effective use of language, effective information presentation, and customisation principles; as well as a lack of error prevention, minimisation of cognitive load (alert fatigue), and feedback (Zahabi, Kaber and Swangnetr, 2015[31]). A recent US study reveals other problems caused by EHRs, such as medication errors in the form of improper dosing, prescribing/dispensing the wrong drug, or an in principle correct drug at the wrong time (Ratwani et al., 2018[32]).

Moreover, in the United States, a study commissioned by the American Medical Association found that many doctors cited EHRs as a major source of burnout (Friedberg et al., 2013[33]). The problem lies partly in their poor design, and partly in the fact that EHRs have become enablers for third parties who wish to ask doctors and nurses to document additional pieces of information (for billing, quality measurement, etc.), which turns clinicians into "expensive data entry clerks". One sign of this documentation burden is the significant growth in the number of individuals hired to provide real-time EHR documentation – the so-called scribes –, allowing physicians to devote more time again to providing care to their patients, but still incurring additional costs on the health system (The National Advisory Group on Health Information Technology in England, 2016[10]).

People-centeredness is important in the design and implementation of digital technology

To avoid technology getting in the way of work, digitisation needs to be perceived as an essential tool for meeting the needs of patients, their families, and health professionals. To avoid the implementation of systems that can create opportunities for errors and can result in frustrated health professionals and patients, health IT systems must be designed with the input of end-users, employing basic principles of user-centred design (see also Box 4.6 below). Also, the digitalisation efforts should not simply digitise the existing analog processes, which might be less effective and/or efficient (The National Advisory Group on Health Information Technology in England, 2016[10]).

Furthermore, given the relative ease with which yet another and yet another data field can be added in an already existing electronic system, an even bigger conscious effort than in the pre-digital era must be made to ascertain that only such information is collected that is absolutely vital (directly or indirectly) for a patient, so as to not waste time and other resources that could be invested in the patients' health by collecting non-essential data.

Last but not least, the digital data system's implementation itself (plus getting used to employing it) takes a considerable amount of time of almost every front-line health worker in a health system and must be accounted and allowed for. This is also another reason why only thoroughly tested and vetted final versions should be rolled out, as having to deal with and to correct dysfunctional ("beta-")versions and getting used to ever changing new versions wastes huge amounts of work hours which have to be taken away from patient care and which still have to be paid for. In this context, the worst possible outcome could even be – and has been in a number of OECD countries – completely failed implementation attempts, due to insufficient preparation at various levels, which waste(d) resources (Watcher, 2015[30]; The National Advisory Group on Health Information Technology in England, 2016[10]). Notably, the waste of resources reported for known incidences only comprise the direct investment into the data system, not the resources (time) wasted by various actors in the health system during the failed implementation attempt.

4.3.4. Legal and ethical questions must be addressed

The stakes are decisively higher when a digital tool affects clinical outcomes rather than travel arrangements, the shipping of products, or the selection of a car insurance policy. While it is widely recognised that advances in data analytics have and will continue to change the practice of health care, the development of adequate professional and ethical frameworks is lagging behind in most countries.

Professional associations of health workers only recently began to explore legal implications of the use of AI in health care, such as issues of liability or intellectual property, and advocate for appropriate professional and governmental oversight for safe, effective, and equitable use of as well as access to AI related tools (AMA, 2018; CPME, 2019b). In effect, health workers face unanswered questions about their and the machines' roles, about the implications for accountability, or about how to ensure that digital systems do not crowd out patient-provider shared decision making.

It is of utmost importance to ensure not only that digital tools such as AI are evidence-based, trustworthy, and patient-centric, but also that they are respecting core ethical principles (CPME, 2019a).

A key policy challenge is to update professional and ethical frameworks, such that health workers have answers to questions about how to work with machines, AI in particular. Even relatively simple machine-learning models already used – such as those automatically stratifying patients into at-risk and intervention groups – give rise to questions regarding the health workers' and the machines' respective roles, accountability, or, again, about how to ensure that digital systems do not crowd out shared decision-making between patients and providers. For example, questions concern how to communicate to a patient when a risk-prediction model did not recommend a treatment, or what mechanism exists to override the model's recommendation, or what happens if following the model's recommendation leads to a suboptimal outcome (of course bearing in mind that it is unknown whether a better outcome could have been achieved by taking a different course of action).

Health professionals must trust the digital tools at their disposal

Health professionals report that they hesitate using digital tools also due to a lack of insight into their design. The current practice of digital tools being developed with little or no insight and input from health workers must be adapted to ensure that sufficient information on their design and quality of the data used is not only made available by the producers, but that relevant health professionals are involved in the development process. Recent high-profile failures, such as the demonstrably incorrect treatment

recommendations produced by IBM's 'Watson' in cancer care due to questionable (but not fully disclosed) data inputs, serve to highlight the challenges. A key problem was that Watson was trained on hypothetical data (as opposed to real-world data), which highlights the importance of strong data governance to ensure transparency and enable putting real-world data to work for productive purposes (see Chapter 8 for further discussion).

4.4. Addressing barriers to health workforce engagement and transformation in the digital era

Addressing the barriers to enable the health workforce to engage with digital transformation and use digital technology to improve their work as well as its outcomes requires action on a range of fronts. Firstly, investments are needed in building trust among health workers – through the adoption of suitable ethical and legal frameworks –, in developing digital skills of front-line health workers, as well as in building a cadre of clinical leaders with expertise in IT and change management. Health-professions education and workforce planning must be addressed to ensure that education and training – with regard to numbers, categories of health workers, and their skills – do not remain static but support strong ties across the education to practice continuum. Moreover, health workers must be actively engaged in the design and implementation of the digital technologies that they are meant to use in order to avoid usability issues and reduce the margin for new type of errors. Finally, the health workers' time needed for the digital data system's implementation itself (plus getting used to employing it) must be accounted and allowed for.

4.4.1. Investing in digital skills of front-line health workers

Higher education institutions and/or professional associations usually lead the transformation of health educational and training curricula in the OECD countries. With regard to digital skills, health education institutions have been expanding the educational content in most OECD countries in the recent years. There has also been a considerable research effort going into the development of digital health competency frameworks to inform the required changes in the education of health workers, in particular nurses and physicians. The largest international project in this field has been the already mentioned 2016-2018 *EU-US eHealth Work Project*, which, among other outputs, produced an international competency framework as well as commensurate educational content for advancing the digital skills of the front-line health workers (EU*US eHealth Work Project, 2019[27]).

Nevertheless, the progress in the adoption of the new digital health education content has been slow, as evidenced by, for example, the recent call for inclusion of educational formats on digital health in medical curricula by the European Association of Medical Students (EMSA, 2019[26]).

Over the last five years, a number of OECD countries – Australia, Canada, Norway, New Zealand, Switzerland, and United Kingdom – undertook expert consultations to establish how technological innovations are likely to change the skill requirements, with the view to inform the transformation of educational and training curricula in digital health. In the United Kingdom, for example, the NHS, on behalf of the Secretary of State for Health and Social Care, established an independent inter-disciplinary expert consultation group, which over 2017-19 worked on describing emerging skills needs as well as roles and functions of health workers, including the consequences for the education of future and the training of current health workers. The report issued in early 2019 (referred to as the *Topol Review*) formulated a set of general recommendations for educators, professional and regulatory bodies, as well as the NHS (Health Education England, 2019a[5]) – (Box 4.2).

Box 4.2. United Kingdom – Educational recommendations for educators, employers, and professional bodies to support a digitally enabled health system.

The *Topol Review*

Professional, Statutory, and Regulatory Bodies need to identify the knowledge, skills, professional attributes, and behaviours needed for health care graduates to work in a technologically enabled service, and then work with educators to redesign the curricula for this purpose.

Education providers should ensure genomics, data analytics, and AI are prominent in undergraduate curricula for health care professionals. Future health care professionals also need to understand the possibilities of digital health care technologies and the ethical and patient safety considerations. Education providers must ensure that students gain an appropriate level of digital literacy at the outset of their study for their prospective career pathway. They should offer opportunities for health care students to intercalate in areas such as engineering or computer science, and equally attract graduates in these areas to begin a career in health, to create and implement technological solutions that improve care and productivity in the NHS.

NHS organisations will need to develop an expansive learning environment and flexible ways of working that encourage a culture of innovation and learning. To do this they will need to have a strong workplace learning infrastructure, cultivate a reputation for training and support, develop learning activities which are proactive rather than reactive, and allow staff dedicated time for development and reflection on their learning outside of clinical duties. The NHS and local organisations should support the development of a cadre of educators and trainers who can lead the educational programme to ensure timely upskilling of the workforce. These organisations also need to put in place systems to identify and develop talented, inspiring new educators within the workforce.

The specialist workforce and specialist teams will be working at the very forefront of their disciplines, often being early adopters of new technologies. Supporting these individuals and teams will be important for continued innovation. In order to support specialists and specialist teams in genomics, digital medicine, AI, and robotics the NHS should develop or expand both educational programmes (for example, the Higher Specialist Scientist Training) and attractive career pathways for both existing and new roles addressing skills gaps in clinical bioinformatics, digital technologies, AI, and robotics. Flexible and responsive training for specialist roles should be introduced. This may include engaging with industrial learning organisations and developing placements, exchanges, and secondments. The NHS should also work with Professional, Statutory, and Regulatory Bodies to introduce and strengthen the accreditation of newer specialist groups.

Source: Health Education England (2019a[5]) "Preparing the health workforce to deliver the digital future", https://topol.hee.nhs.uk/wp-content/uploads/HEE-Topol-Review-2019.pdf.

Some countries have introduced guidelines on integrating digital technology in education and training

Governments in some of these countries also lead initiatives that either issue concrete guidelines on how to integrate digital health topics into health workers education and training programmes or support the development of networks within which educational institutions and other actors – usually professional associations and/or health sector employers – can pool their expertise and resources in the modernisation of the educational and training curricula.

In the "Swiss eHealth Strategy 2.0", for example, empowering the health workers to know and efficiently use ICT tools is a declared field of action with several goals. Accordingly, in 2017, eHealth Swiss – the Swiss Competence and Coordination Centre of the Confederation and the Cantons – has published guidelines for educators on how to integrate eHealth topics into the education and professional training of health workers (eHealth Suisse, 2017[34]). eHealth Suisse leads also a national coordination group on eHealth education with members including educational institutions along with professional associations and umbrella organisations of the health sector employers.

Similarly, Canada Health Infoway – an independent, not-for-profit organisation, fully funded by the federal government – works collaboratively with the provinces and territories (PTs) to promote the active engagement of health care providers involved in the implementation of digital health systems across Canada. Infoway funds a number of initiatives led by educational and accreditation bodies to help prepare the future health workforce. An example is the Association of Faculties of Medicine of Canada (AFMC) initiative to better prepare medical students to practice in an ICT enabled context. Its work led to the development of the eHealth Competencies for Undergraduate Medical Education and the AFMC Infoway eHealth Workshop Toolkit Collection.

Infoway has also worked with the Canadian Association of Schools of Nursing (CASN) and the Association of Faculties of Pharmacy of Canada (AFPC) on initiatives aimed at improving the preparedness of nursing and pharmacy graduates to work in a technology enabled environment. In partnership with those organisations (AFMC, AFPC and CASN), Infoway has developed the Digital Health Faculty Associations Content & Training Solutions (FACTS) initiative. The Digital Health FACTS program engages faculty and students from 17 Faculties of Medicine, 10 Faculties of Pharmacy, and 94 Schools of Nursing to scale and spread education in digital health, promote an interdisciplinary and cross-sectoral approach, as well as develop practical resources for faculty and students to employ digital tools toward interprofessional, collaborative patient care.

In other countries, health sector employers strive to partner with local educational institutions to ensure an adequate supply of digitally skilled health professionals. In Australia, for example, Metro South Health –one of Queensland's largest health services by population and employed staff – works together with universities as well as training providers to ensure future employees have the needed knowledge and skills (HealthcareIT, 2019[35]). These efforts regard a wide range of digitally-focused roles within health care, including not only front-line health workers, but also project managers and business analysts with IT skills, an ability to improve processes, and an understanding of how to design solutions for patients as well as clinicians.

Investment in digital health infrastructure needs commensurate investment in health workforce skills

How and whether the recommendations formulated for educators, professional and regulatory bodies, and/or employers will be acted upon remains to be seen. Indeed, in most OECD countries much remains to be done to ensure that the skills health workers need for an effective and safe use of existing and emerging digital technologies are taught routinely.

In the majority of countries, the pace of changes has been particularly slow with regard to Continuous Professional Development (CPD) programmes. Most often, to the health workers, suppliers of the technology provide a one-off training, but these frequently address only basic operational issues and are technology specific. In the public sector, health professionals often lack basic training support as digital systems, such as electronic health records, are being introduced (Aerzte Zeitung, 2019[36]; House of Lords, 2017[37]). In short, investments in rolling out digital health services infrastructure are not always accompanied by the commensurate investments in health workforce training.

As an example of coordinated investments, the Australian Government's Digital Health Agency – responsible for all national digital health services and systems – in addition to rolling out a digital health

services infrastructure, also provides on-demand training to health care organisations and developed a range of software demonstrations as well as training platforms for health workers to facilitate self-paced training. Health professionals can, for example, familiarise themselves with the digital health functions in their EHRs software without the need for a real patient (Australian Digital Health Agency, 2019[38]). In the United States, the 2009 HITECH Act – created to motivate the implementation of EHR and supporting technology – funded two distinct health IT workforce training programs – the University-Based Training Program and Community College Consortia Program – which supported training of more than 20 000 working professionals and students between 2010 and 2013 (ONC, 2019[39]).

4.4.2. Investing in clinical IT leaders and a cadre of informaticians with clinical expertise

Programmes and accreditation standards in Health or Clinical Informatics[3] have existed in the majority of the OECD countries for some decades now. First programmes appeared already in 1960s in France, Germany, Belgium, and the Netherlands (Haux, 2010[40]). Frequently, the field has been defined as "the interdisciplinary study of the design, development, adoption and application of IT-based innovations in health care services delivery, management and planning" (National Library of Medicine, 2019[41]). The field has been, however, primarily clerical, including positions predominantly involved with the collection, handling, and processing of health information (usually patient records) for the purpose of accurate billing, and much less often for other purposes, such as quality assurance or an improvement in patient care.

Only more recently, Big Data and a shifting focus on population and patient outcomes have reshaped the field of clinical informatics and resulted in a more diverse set of roles, such as Clinical Analysts or Chief Information Officers, which involve sophisticated, judgment-based work aiming at improving the effectiveness and efficiency of health services delivery. However, as discussed earlier, these developments in the Clinical Informatics programmes seem to lag behind the demand for workers who can meet the modern requirements of managing health information. In Europe, for example, Tallinn University of Technology offers a unique Master's programme in Health Care Technology that combines interdisciplinary knowledge of eHealth technologies, financing and change management in health care, medical imaging and signals, as well as medical law and ethics, among other subjects (Tallinn University of Technology, 2019[42]).

Hybrid skills covering clinical leadership and informatics are needed

Moreover, there seems to be room for improvement in the development of education programmes (as well as of the corresponding jobs with sustained career pathways) that closely tie clinical leadership and IT content to produce more of the hybrid skill combinations that the health sector is demanding. Since 2009, there has been a substantial progress in this area in the United States, where the universities and health care organisations have substantially increased the number of informatics fellowships, expanded their health informatics capability, and substantially increased the number of senior clinical leadership positions in informatics and digital transformation (Kannry et al., 2016[43]).

In the United Kingdom, the launch of the NHS Digital Academy in 2017 (Sood and Keogh, 2017[11]) should help accelerate progress. The NHS Digital Academy has been commissioned by NHS England and is delivered by a partnership of the Imperial College London, the University of Edinburgh, and the Harvard Medical School, with funding of GBP 6 million. The aim is to develop a new cadre of at least 300 IT leaders to support the information and technology transformation of the NHS. The Academy provides a year-long, fully accredited and funded programme (Post-Graduate Diploma in Digital Health Leadership) to upskill NHS managers and lead clinicians (e.g. Chief Information Officers, Chief Clinical Information Officers). The programme combines content in leadership and change management, health informatics and data analytics, health systems and user-centred design, as well as citizen informatics, among other subjects. In order to be considered for the NHS Digital Academy, applicants are required to have executive level support from their NHS organisation (NHS England, 2019[44]; Imperial College London, 2019[45]).

4.4.3. Health education governance and health workforce planning require a new approach

As mentioned earlier, in OECD countries, the content of the education programmes for health professionals and their restructuring is typically influenced by higher education institutions and/or professional associations. However, in some countries, governments have initiated measures to increase the influence of other actors, such as health sector employers.

In 2019, the Norwegian Government has actually established a new governance system for determining learning outcomes in health and social education programmes. A key feature of the new system are education specific program groups consisting of representatives of both the education institutions and the health and social service, which revise as well as, if needed, propose new learning outcomes for each education field. The aim is to ensure that the learning outcomes are updated at regular intervals to reflect any emerging skills needs (Box 4.3).

Box 4.3. Outcome-based national curriculum regulations for Norwegian health and welfare education

The Norwegian government is currently in a process of major restructuring of National Curriculum Regulations in health and welfare education with the aim to make these more future-oriented. The restructuring is based on acknowledging that curricula easily can become too static and fail to adapt to the rapid changes taking place in the related services. New technology, new professional knowledge, changing demographics, and major service delivery reorganisations have shifted the required skill mix. The restructuring is a collaborative effort of the Ministry of Education and Research, the Ministry of Labour and Social Affairs, the Ministry of Children and Families, as well as the Ministry of Health and Care Services.

So far, the restructuring process has led to the adoption of a new National Regulation relating to a common curriculum for health and welfare education that includes 12 learning outcomes common to all study programmes, as well as regulations introducing national (uniform) curricula for each study programme.

One of the key features of the new governance system is the establishment of programme groups for each programme of education, of which half of the members come from higher education institutions, and the other half represents employers in health and social care. Each group also includes a student representative. The programme groups are tasked with preparing curricula and, later, reviewing as well as revising them, if needed. The groups operate within RETHOS – a project organised under the Ministry of Research and Education. The intention is that the curricula will function dynamically and be amended as needed. The curricula include the learning outcomes, the structure of the programme, and requirements regarding the practice-based parts of the studies. The learning outcomes are to be formulated in accordance with the National Qualifications Framework and define the minimum requirements relating to graduates' final competencies. The curricula are to be phrased on a medium level of detail to allow leeway for possible local adaptations at the higher education institutions. The curricula will be implemented in 2020-21 and must be adhered to by all respective higher education institutions.

At present, the new governance system covers the national curricula leading to the following qualifications: Audiologist, Child welfare officer, Clinical Nutritionist, Dentist, Dental hygienist, Dental technician, General Nurse, Medical Laboratory Technologist, Occupational therapist, Optometrist, Paramedic, Pharmacist (both head pharmacist and dispensing pharmacist), Physiotherapist, Physician, Prosthetist, Psychologist, Radiographer, Social educator, and Social worker. There are also plans for RETHOS to cover specialisation programmes in the near future.

Source: RETHOS, Ministry of Research and Education, 2019.

Some countries strive also to adopt new tools and techniques in health workforce planning, with the aim of securing not only the right number of existing categories of health workers but also of timely recognising the need for new professional categories/roles and avoiding a mismatch between skills possessed by the health workers and those required in day-to-day practice. These new tools and techniques can be adapted to deliver a workforce with the right skills and career opportunities needed to realise the full potential of digitalisation and electronic health data.

New Zealand's recent workforce policy and planning approach, for example, has adopted new tools and techniques to better identify skills and roles needed for modern and emerging care models. The agency created for this task – Health Workforce New Zealand (HWNZ) – seeks to understand how future services may be configured by applying a method influenced by design thinking to better respond to future health needs (Ministry of Health, 2014[46]; Ministry of Health, 2016[47]; Rees, 2019[48]). This approach extends the conception of health workforce data beyond the traditionally collected quantitative data to recognise qualitative workforce intelligence. It includes, for example, the use of Work Service Forecasts (WSFs), where clinically-led teams describe future scenarios of care. HWNZ has begun to incorporate the results of WSFs into its planning system (Box 4.4). However, the policy challenge HWNZ is now confronted with is aligning the new governance methods with implementation (Rees, 2019[48]).

Box 4.4. Health Workforce New Zealand and its rethinking of workforce policy and planning

Health Workforce New Zealand (HWNZ) – established in late 2009 – is an agency charged with providing national leadership for the development of the country's health and disability workforce and with the overall responsibility for planning and development of the health workforce to ensure that it is fit for purpose (Ministry of Health, 2014[46]; Rees, 2019[48]).

While continuing to use traditional workforce forecasting methods, HWNZ has extended the range of tools that it has at its disposal. Their application has enabled the use of a wider range of planning methods to develop broader workforce intelligence variables. The agency reconsidered how health workforce planning may proceed and sought to understand how future services may be configured to better respond to future health needs (Rees, 2019[48]).

One of the most significant changes that HWNZ implemented was to adopt an approach of workforce planning that embraced conditions of uncertainty and to conceive new visions of health services. Operationalising this approach led to the development of the Work Service Forecast (WSF), a clinician-led and patient-centred scenario, resulting in a forecast of possible future model(s) of care for a particular service aggregate. The process of developing HWNZ's thirteen WSFs from 2010 to 2013 was designed to reduce the system's reliance on profession-by-profession forecasting while accommodating inherent uncertainty and emerging workforce and treatment innovations (Ministry of Health, 2014[46]). The WSF development process uses a wider range of forecasting methods and techniques, such as scenarios, stakeholder workshops, and expert panels, while incorporating broader workforce intelligence variables to generate its demand-supply predictions. The methodology incorporates aspects of design thinking – a planning process that uses reflection and analysis, visualising, modelling, as well as planning to trial – test and implement a solution for a problem (Rees, 2019[48]).

The introduction of the new WSF process met with some resistance, which is, however, not unusual with new planning methods or approaches. Even so, the WSF process was found to have been a successful means for bringing together interdisciplinary groups of professionals, building capacity, and developing new ways of thinking about services and workforce plans (Naccarella, Greenstock and Wraight, 2013[49]).

HWNZ is also introducing more qualitative intelligence through a scope of practice analysis, in particular their scope overlap or plasticity analysis investigates the possible substitution of professionals at some stages of care (Rees, 2019[48]).

4.4.4. Reinforcing health workers' trust and promoting engagement in the development of digital technologies

Trust will play a crucial role in the uptake of digital innovations, AI in particular, in daily health care practice. Both health professionals and patients might need convincing of the reliability and safety of AI and its positive contribution to the care process. A key policy challenge is to timely update professional and ethical frameworks, such that health workers have answers to questions about how to work with machines. Any delay makes health professionals hesitant to use data-enabled digital tools or other technologies that enhance cooperation among providers across settings.

The 2019 OECD Recommendation on Artificial Intelligence can guide countries in this regard (OECD, 2019[50]). The Recommendation recognises that AI has the potential to improve the welfare and well-being of people, to contribute to positive sustainable global economic activity, to increase innovation and productivity, and to help respond to key global challenges. The Recommendation considers, however, that, at the same time, AI may have disparate effects within, and between societies and economies, notably regarding economic shifts, competition, transitions in the labour market, inequalities, as well as implications for democracy and human rights, privacy and data protection, and digital security. The Recommendation therefore stresses that that:

- trust is a key enabler of digital transformation;
- although the nature of future AI applications and their implications may be hard to foresee, the trustworthiness of AI systems is a key factor for the diffusion and adoption of AI;
- a well-informed whole-of-society public debate is necessary for capturing the beneficial potential of the technology, while limiting the risks associated with it.

While the document recognises that certain existing national and international legal, regulatory, and policy frameworks already have relevance to AI – including those related to human rights, consumer and personal data protection, intellectual property rights, responsible business conduct, as well as competition – it also notes that the appropriateness of some frameworks may need to be assessed and new approaches developed. Accordingly, it provides governments with a set of principles for a responsible stewardship of trustworthy AI that include:

1. pursuit of inclusive growth, sustainable development, and well-being;
2. respect of human-centred values and fairness;
3. commitment to transparency and explainability;
4. ensuring of robustness, security, and safety; and
5. accountability for the proper functioning of AI systems (Box 4.5) (OECD, 2019[50]).

Box 4.5. OECD Council's principles for responsible stewardship of trustworthy AI

The following principles are complementary and should be considered as a whole.

Inclusive growth, sustainable development and well-being

- Stakeholders[1] should proactively engage in a responsible stewardship of trustworthy AI in pursuit of beneficial outcomes for people and the planet, such as augmenting human capabilities and enhancing creativity, advancing inclusion of underrepresented populations, reducing economic, social, gender and other inequalities, and protecting natural environments, thus invigorating inclusive growth, sustainable development, as well as well-being.

Human-centred values and fairness

- AI actors[2] should respect the rule of law, human rights, and democratic values, throughout the AI system lifecycle. These include freedom, dignity and autonomy, privacy and data protection, non-discrimination and equality, diversity, fairness, social justice, as well as internationally recognised labour rights.
- To this end, AI actors should implement mechanisms and safeguards, such as the capacity for human determination, that are appropriate to the context and consistent with the state of art.

Transparency and explainability

- AI actors should commit to transparency and responsible disclosure regarding AI systems. To this end, they should provide meaningful information, appropriate to the context, and consistent with the state of art:
  - to foster a general understanding of AI systems,
  - to make stakeholders aware of their interactions with AI systems, including in the workplace,
  - to enable those affected by an AI system to understand the outcome, and,
  - to enable those adversely affected by an AI system to challenge its outcome based on plain and easy-to-understand information on the factors, and the logic that served as the basis for the prediction, recommendation, or decision.

Robustness, security, and safety

- AI systems should be robust, secure, and safe throughout their entire lifecycle such that, in conditions of normal use, foreseeable use or misuse, or other adverse conditions, they function appropriately and do not pose an unreasonable safety risk.
- To this end, AI actors should ensure traceability, including in relation to datasets, processes, and decisions made during the AI system lifecycle, to enable the analysis of the AI system's outcomes and responses to inquiry, appropriate to the context and consistent with the state of art.
- AI actors should, based on their roles, the context, and their ability to act, apply a systematic risk management approach to each phase of the AI system lifecycle on a continuous basis to address risks related to AI systems, including privacy, digital security, safety, and bias.

Accountability

- AI actors should be accountable for the proper functioning of AI systems and for the respect of the above principles, based on their roles, the context, and consistent with the state of art.

1. Stakeholders include all organisations and individuals involved in, or affected by, AI systems, directly or indirectly.
2. AI actors are a subset of stakeholders, i.e. those who play an active role in the AI system lifecycle, including organisations and individuals that deploy or operate AI.

Source: OECD (2019[50]) "Health system accounts", https://stats.oecd.org/.

Digital tools must be designed with the input of end-users

Furthermore, health professionals report their hesitancy in using digital tools also due to a lack of insight into their design and due to the fact that some digital systems and tools simply lack usability. The still prevalent practice of digital tools being developed using hypothetical clinical data and/or with little or no input from health professionals must be adjusted to ensure that sufficient information on their design is not only made available by the producers but that relevant health professionals are involved in the design process.

The experience of other industries illustrates clearly that digital tools must be designed with the input of end-users, employing basic principles of user-centred design (Box 4.6). The usability of technology is one of the major drivers of its widespread adoption and use in everyday life. Usability also affects the quality of the data collected, and is thus a major determinant of the power of analytics (The National Advisory Group on Health Information Technology in England, 2016[10]).

Creating and enacting campaigns to engage front-line health workers should be a fundamental part of the digital transformation in every organisation in the health sector. Health care provider organisations and funders should also consider supporting academic or other partners in research assessing the usability of emerging digital systems and tools using validated assessment methodologies. Such reviews could then factor into decisions regarding purchasing and implementation of the digital systems and tools (The National Advisory Group on Health Information Technology in England, 2016[10]).

Box 4.6. Human-Centred Design and implementation of digital tools in health care

Using human-centred design (HCD) is becoming a trend across industries and organisations, which share the perspective that any effort to improve a system, its processes, or its products and services must begin with customers and the people doing the work.

In the health sector, HCD can help bridge the gap from developing a new idea to broad use by ensuring that the implementation is more people-centred and positions new solutions in a way that speaks to staff and patients. HCD focuses on human needs and helps identify which parts of a process matter most to people and how the process fits into their jobs (health workers) and lives (patients). It simply helps to avoid working on the wrong problem. HCD also provides a framework for more deeply connecting diverse stakeholders in collaborations that generate creative interdisciplinary solutions.

For example, a Kaiser Permanente Northwest team has been working on how to better support family caregivers of patients with dementia. Patients and caregivers are often unclear about what follows an initial diagnosis by a primary care provider (PCP), while the providers often feel inadequately equipped with resources to address next steps. A group that included family caregivers, PCPs, memory clinic specialists, social workers, and an Alzheimer's Association representative created a prototype of a pre-configured electronic health record feature to trigger appropriate referrals that PCPs could use to initiate a smooth and timely care path. PCPs who didn't participate in the co-design session tested the prototype, reporting that their confidence about providing appropriate support and resources for caregivers increased more than threefold, from 1.8 to 6.2 on a 10-point scale. The feature met the needs of caregivers, PCPs, and social workers and is currently poised for spread throughout Kaiser Permanente Northwest. In general, Kaiser Permanente staff members who were using HCD methods in performance improvement and innovation work, reported feeling that they "*rediscovered joy in their work and 're-engaged with the organizational mission'*", and that HCD helped them "*see the value in the services they provide*".

Source Kachirskaia, Mate and Neuwirth: (2018[51]), "Human-Centered Design and Performance Improvement: Better Together", https://catalyst.nejm.org/hcd-human-centered-design-performance-improvement/.

4.5. Conclusion

A digitally capable and enabled workforce is needed to embrace the use of technology and data. The experience from within the health sector as well as other industries demonstrates that investing only in the digital infrastructure without engaging the workforce and supporting the development of new skills does

not allow to realise the full potential of digital innovations. In fact, the technology can even get in the way of work.

In particular in the health sector, putting technology to productive use requires a balanced approach; using digital data effectively is not simply about the technology, it is mostly about the people by which it is used but also those for which it is used, i.e. the patients. Therefore, any national eHealth strategy should involve a thoughtful blend of funding and resources for infrastructure, and, the often missing support for the engagement as well as the education and training of the health workforce.

Whether and how the emerging skills needs are identified and addressed defines the success of the digital transformation in health service delivery. Governments in some countries are already making structured efforts to assess the skills demanded and the commensurate implications for health workers education and training, or actively engage in amending the health education and training curricula. However, much remains to be done. Evidence suggests that, currently, the front-line health workers do not feel sufficiently prepared and health care organisations lack a cadre of clinician leaders with the necessary skills in health care improvement and redesign of care enabled by digital technologies. Additionally, there is a lack of workforce capacity amongst both clinician and non-clinician informatics professionals. This deficit poses a serious barrier to progress and needs to be remedied.

The early efforts to build the required capacity within the health workforce will need to be supported and expanded. In particular, more attention needs to be directed to the Continuous Professional Development programmes to ensure that the skills the current health workers need for an effective and safe use of emerging digital technologies are taught routinely and that the health workers have time to acquire them.

Furthermore, both the issues of skills supply and demand need to be considered simultaneously, in particular for the very much needed cadre of clinical leaders in digital technology. Without the availability of full-time jobs with a sustainable career track, few talented individuals will choose to leave the practice of clinical medicine, nursing, or pharmacy to obtain additional training and certification in health information technology.

Health jobs are unlikely to be automated in the foreseeable future. However, as technology augments health workers' tasks and roles, regulations need to allow for expanding or reassigning these tasks and roles. The augmented workflows need to be recognised in provider reimbursement models to allow the technology to add value. Therefore, health sector employers need to be incentivised to embrace new technology and recognise the need for change in the workforce and work processes. Otherwise, the adoption of digital technologies might simply lead to digitising the current analogue processes without increasing effectiveness and efficiency. The digital data system's implementation itself (plus getting used to using it) takes a considerable amount of time of almost every front-line health worker in a health organisation and must be accounted and allowed for.

Moreover, in order to avoid the implementation of systems that can create opportunities for errors and can result in frustrated health professionals and patients, digital tools and systems must be designed with the input of end-users, employing basic principles of user-centred design. The current practice of digital tools being developed with little or no insight and/or input from health workers must be adjusted to ensure that sufficient information on their design and quality of the data used is not only made available by the producers, but that relevant health professionals are involved in the design process. Creating and enacting campaigns to engage front-line health workers should be an integral part of the digital transformation in every organisation in the health sector. Health care provider organisations and funders should also consider supporting academic or other partners in research assessing the usability of emerging digital systems and tools using validated assessment methodologies. Such reviews could then factor into decisions regarding the purchasing and implementation of the digital systems and tools.

Finally, there is also a need to update professional and ethical frameworks along with educational and training curricula and work processes, such that health workers can trust, and know how to work with the machines, AI in particular. The stakes are decisively higher when a digital tool affects clinical outcomes

rather than consumer-oriented tasks in the wider economy. While it is widely recognised that advances in data analytics have and will continue to change the practice of health care, the development of adequate professional and ethical frameworks is lagging behind in most countries. Professional associations of health workers only start to explore the legal implications of the use of AI in health care, such as issues of liability or intellectual property, and advocate for appropriate professional and governmental oversight for a safe, effective, and equitable use of and access to AI related tools.

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Notes

[1] See also Chapter 2.

[2] In the figure, the comparatively small estimated risk of automation for health sector jobs is even biased upwards. This is because the data used does not include some of the job tasks typical for most health sector jobs – for example, some tasks that have to do with direct patient care (caring for and assisting others) – that are especially difficult to automate, given the current state of knowledge. In effect, the probability of automation for the health sector jobs is calculated based on only a (small) subset of the tasks that are found in the majority of health sector jobs.

[3] Also called health care informatics, health care informatics, medical informatics, nursing informatics, or biomedical informatics.

5 Big data: A new dawn for public health?

Cristina Gall and Elina Suzuki

Changing disease patterns and escalating costs of care make prevention, health promotion and public health pressing concerns and key parts of addressing the challenges facing health systems. Already, the technical capacity exists to pursue a new type of ‘precision’ public health – applying the principles and technology of precision medicine to disease prevention and public health policy. As the need for evidence-based policies grows, big data seems to hold the key to dramatic, rapid improvements to help promote health and prevent disease. At the same time, health systems have been slow to adopt new technologies, and must consider how these new approaches will affect privacy. In the face of these developments, public health policy makers need to discern the most effective ways in which they can leverage big data, as well as how to best address the challenges associated with these novel technologies.

5.1. Introduction

Big data keep getting bigger. It is estimated that 2.5 quintillion bytes of data are now created daily – that is, 2.5 billion billion or $2.5x10^{18}$ bytes (IBM, 2017[1]). 90% of the data in the world today were created in the last few years alone (DOMO, 2017[2]). By 2020, it is estimated that 1.7 megabytes of data will be created every second for every person in the world (DOMO, 2018[3]). As the capacity to generate and analyse large amounts of data continues to increase worldwide, the term "Big Data" has become ubiquitous. Big data are increasingly relevant to many different kinds of research and knowledge creation activities, across a variety of domains (Box 5.1).

The chapter explores the possibilities, risks and challenges of deploying Big Data in in the sphere of public health. As the need for evidence-based policies becomes increasingly pressing, big data and their associated analytic tools hold the promise of vastly improved strategies to promote health and prevent disease. In the face of these developments, public health policy makers need to discern the most effective ways in which they can leverage big data, as well as how they can best address the challenges associated with these novel technologies.

Big data, and big data analytics, can be used at all three levels of health promotion and disease prevention – research, surveillance, and intervention – by:

- **Allowing a more precise identification of at-risk populations**, through a more comprehensive understanding of human health and disease, including the interaction between genetic, lifestyle, and environmental determinants of health;
- **Enabling better surveillance** of both communicable and non-communicable diseases; and
- **Facilitating better targeted strategies and interventions** to improve health promotion and disease prevention.

The public health sector, however, has been a relatively slow adopter of big data analytics. While efforts to leverage big data in public health policy making are starting to gain momentum, such as the European Union's "Big Data supporting Public Health policies" programme, there is a need for a more systematic focus on and resource allocation for such initiatives. In a recent OECD survey, few respondents reported using any kind of non-traditional data sources for public health, and most of these initiatives are still in exploratory stages. Even when big data sources are used, such initiatives are typically limited to disease surveillance and the identification of isolated risk factors.

Using big data primarily for knowledge accumulation, rather than effective interventions, can be problematic: while harnessing big data can help answer many questions, it can also exacerbate the *"A lot is known, but little is put into practice"* policy dilemma. In other words, a risk also exists in deploying scarce resources to accumulate more health knowledge that then remains unused. Leveraging big data to help distil knowledge into clear public health interventions remains a major challenge. Though limited in scope, existing examples – such as Geisinger's GenomeFIRST initiative, which identifies patients at a high risk of treatable conditions, through whole exome sequencing – underscore the potential of harnessing new data for prevention and care. But such programmes need to be validated and applied at scale.

Box 5.1. Big data – a primer

Defining Big Data

The term "Big Data" is often poorly defined. In practice, it is "often described 'implicitly' through success stories or anecdotes, characteristics, technological features, emerging trends or its impact to society, organizations and business processes" and in reference to "a variety of different entities including social phenomenon, information assets, data sets, analytical techniques, storage technologies, processes and infrastructures" (De Mauro, Greco and Grimaldi, 2015[4]). The term "big data" is also frequently intertwined with the concept of "big data analytics" (Box 5.2). Various formal definitions have been proposed, which share a set of concepts and characteristics (De Mauro, Greco and Grimaldi, 2015[4]; Sivarajah et al., 2017[5]).

- **High volume**: the large scale of data sets.
- **High velocity**: the high rate of data inflow, as well as the speed with which it needs to be processed and analysed.
- **High variety**: the heterogeneity of data (i.e., diverse and dissimilar data formats).
- **Specific data extraction and analysis methods**, collectively known as "big data analytics".
- **Value creating**: producing valuable insights, which cannot be obtained from traditional data sources.

"Big Data" can be structured, semi-structured, or unstructured, and can come from "sensors, devices, video/audio, networks, log files, transactional applications, web, and social media – much of it generated in real time and in a very large scale" (IBM, n.d.[6]). In addition to Volume, Velocity, Variety, and Value, other qualifiers have been proposed – such as veracity (unbiased truthfulness), validity (accuracy), and volatility (whether the data is still valid) – to reflect issues such as data accuracy and utility (Bansal et al., 2016[7]). The concepts of "veracity" and "validity" refer to the need to use analytical methods that can account for the unreliability of big data, such as various biases (IBM, n.d.[8]).

Types and sources of data: an overview

Big data sources that can be used for public health include:

- *Structured* data, e.g. data from electronic medical records (EMR) and electronic health records (EHR), participatory surveillance systems (e.g., crowdsourcing, crowdmapping).
- *Semi-structured* data, e.g., data from health monitoring devices.
- *Unstructured* data, which presents the greatest potential to use non-health data to enhance public health. Sources of unstructured data include, among others:
  - Social media and online data, i.e. "virtual digital trails".
  - Consumption data, i.e. "real-life digital trails".
  - Spatial/geographic data.
  - Physical environment data.

Real-time data, such as sensor data from wearable technologies and environmental sensors that measure variables like air pollution and airborne allergens, can also enable the delivery of more personalised prevention strategies. The large amounts of environmental data (e.g. weather patterns, pollution levels, water quality) collected in non-health sectors can similarly be used to inform public health policies. In the context of climate change, these types of data will become increasingly important, particularly for infectious disease surveillance.

5.2. OECD countries are using new analytical tools to better link electronic health databases and draw policy insights for public health purposes

Results from the 2018 OECD Survey on Uses of Data and Digital Technology indicate that many OECD countries have begun to harness big data for public health purposes, though many of these remain at an early stage of development. These efforts have largely focused on using new improvements in computing and analytical power to take advantage of existing health databases in ways that would previously been too time- or resource-intensive.

In Australia, for example, the Data Integration partnership for Australia (DIPA) has supported the Department of Health to identify adverse events associated with medicines through analysing data from the Pharmaceutical Benefits Scheme. Through analysing data from the Pharmaceutical Benefits Scheme, as well as datasets such as the Medicare Benefits Schedule and hospital discharge data, the Australian government is working towards identifying and acting on medicine safety issues earlier, with the goal of increasing patient safety and reducing hospitalisation and treatment costs.

In the Czech Republic, the National Registry of Reimbursed Health Services, containing comprehensive reimbursement data from health care administrative records, was launched in 2018. The National Registry offers new possibilities to evaluate public health interventions, including screenings. In Norway, digital health information – including health registries and national surveys – have been used to develop municipal and regional public health profiles, which are used actively by municipalities to improve public health and by the media to compare local populations to performance across Norway.

5.2.1. New analytical techniques can enhance public health policy making

Traditional public health is data-poor and has traditionally lacked the key big data characteristics: high volume, high variety, and high velocity. Epidemiologic research generally relies on long-term, longitudinal, relatively small- or medium-scale cohort studies, in which data are gathered through participant questionnaires, physical examinations, and, for outcome data, health records. These data sources are often difficult to obtain and work with. Similarly, public health surveillance – defined as the ongoing systematic collection, analysis, and interpretation of data, as well as the dissemination of these data to public health practitioners, clinicians, and policy makers (Richards et al., 2017[9]) – and public health interventions have traditionally been performed through time-consuming, error-prone methods. These methods pose significant timeliness and efficiency limitations and suffer from time lags and lack of spatial resolution. Table 5.1 summarises the implications of big data for public health.

Table 5.1. Summary of the three Vs of big data and their implications for public health

Name	Meaning	Examples	Opportunities and Challenges	Implications for public health
Volume	Data sets with more observations	National electronic health record databases, social media datasets	Power to precisely measure unexpected associations, though potentially without substantive relevance	Evolutionary/incremental
Variety	Datasets with variables from different sources; more variables per observation	Neighbourhood data added to a phone survey	Capacity to assess complex interactions, but more complicated variable selection	Evolutionary/incremental
Velocity	Data collected and analysed in real-time	Medication adherence intervention messaging adapted to subject response pattern	Potential to design dynamic interventions	Potentially revolutionary

Source: Mooney, Westreich and El-Sayed (2015[10]), "Commentary: Epidemiology in the era of big data", http://dx.doi.org/10.1097/ede.0000000000000274.

However, the development of new analytical techniques has enabled policy makers to harness existing health datasets in ways that can transform existing disparate databases into a larger set of data with key big data characteristics.

In *non-communicable disease prevention*, big data can help better understand and address modifiable behavioural risk factors that contribute to a large fraction of the non-communicable disease burden (e.g. diet, physical activity, tobacco use). Big data analytics (Box 5.2) can enable policy makers to more effectively assess these risk factors at the population, subpopulation, and individual levels, as well as to design better targeted interventions aimed at mitigating them. In particular, big data analytics can help understand, at a causal level, how hereditary risk factors – as well as combinations of risk factors – interact with behaviour and the physical and social environment. In *communicable disease prevention*, hybrid tools that combine traditional methods and big data analytics can enhance communicable disease surveillance by harnessing novel data streams to complement – rather than replace – traditional methods.

Box 5.2. What are big data analytics?

The specialised tools and analytical methods needed to extract useful insights from big data sources are transforming the use of big data for public health. These specialised technologies are collectively known as "big data analytics". Using big data analytics can enhance public health at the research, surveillance, and intervention levels. It can thus enable the design and implementation of more effective, evidence-based public health policies.

Predictive analytics are the most common type of big data analytics. They represent one of the three main types of analytics, the other two being descriptive and prescriptive analytics (Sivarajah et al., 2017[5]). While descriptive analytics are backward looking and are used to measure facts and summarize data, predictive analytics are forward looking and use past or current data to make predictions about the future, through tools such as machine learning, data mining, and statistical models.

- *Machine learning* is an important tool for predictive analytics and refers to the design of algorithms that allow computers to "learn", i.e., progressively improve performance on a specific data-related task by adapting to patterns in data, with the aim of knowledge discovery and automatic decision making (Chen and Zhang, 2014[11]). Machine learning can be supervised, unsupervised, or semi-supervised (Fuller, Buote and Stanley, 2017[12]). While often conflated, machine learning and predictive analytics represent distinct concepts.
- *Data mining*, also known as knowledge discovery, refers to the extraction of potentially useful information from data, often using similar techniques as machine learning (Fuller, Buote and Stanley, 2017[12]).

Prescriptive analytics refer to optimization and randomized testing and address the "So what?" types of questions that arise after the data have been analysed through either descriptive analytics, predictive analytics, or a combination of both (Sivarajah et al., 2017[5]).

5.2.2. Big data can improve the identification of population- and person-level risk factors

The potential of big data to allow for a more precise identification of risk factors is attracting more and more interest from researchers and policy makers alike. An increasing number of large-scale population studies aim to leverage big data to pinpoint specific risk factors more precisely, using more data than traditional epidemiologic studies are able to. There is a particularly enthusiastic focus on identifying hereditary risk factors through genetic testing.

This approach, however, can backfire: the temptation to use big data to find new, exciting risk factors or more precisely measure the effects of known ones could come at the expense of engaging with "the broader causal architecture that produces population health"; in other words, the "proliferation of causal effects – typically identified through an approach that aims to isolate risk factors for particular outcomes – presents a conundrum for scientists, let alone the lay public, to synthesize and form evidence-based recommendations that can promote health." (Keyes and Galea, 2015[13])

The capacity to leverage bigger and better data to measure the effects of precise risk factors therefore needs to be carefully weighed against *what matters most for population health* (Keyes and Galea, 2015[13]). Indeed, the potential of big data to improve public health lies not in better measurements of various isolated risk factors, but in the ability to analyse the complex, dynamic interactions between human behaviour/lifestyle ("behavioural phenotypes"), genetics, and the physical and social environment to determine what matters most for public health policy.

There is therefore a need to move from clinical validity (confirming robust relationships between risk factors and disease) to clinical utility: in other words, when it comes to the public health impact of big-data driven research, researchers and policy makers should address the *"Who cares?"* and *"So what?"* questions.

Furthermore, discussions of big data often go beyond the technological and analytical aspects and suggest a "mythological" dimension: "the widespread belief that large data sets offer a higher form of intelligence and knowledge that can generate insights that were previously impossible, with the aura of truth, objectivity, and accuracy" (Boyd and Crawford, 2012[14])

Bigger is not necessarily better

When it comes to data, however, bigger is not always better. Big data sets, regardless of their size, are subject to biases that need to be well understood and accounted for to avoid misinterpretation and incorrect conclusions. The temptation to over-rely on big data without having robust methodologies in place for interpreting it can lead to *apophenia*: "seeing patterns where none actually exist, simply because enormous quantities of data can offer connections that radiate in all directions" (Boyd and Crawford, 2012[14]). For example, one analysis used data mining techniques to show that a strong, but spurious association could be found between the evolution of the S&P 500 stock market index in the United States and butter production in Bangladesh (Leinweber, 2007[15]).

In addition, big data is not necessarily "whole data": the large size of a data set does not necessarily mean it is a representative sample of a certain population (Boyd and Crawford, 2012[14]). Overlooking this issue when analysing big data sets can lead to biased results. Strong methodological standards for interpreting large data sets and accounting for biases must therefore be at the forefront of big data analysis.

5.3. Harnessing novel data sources represents a new frontier for public health

Integrating and harmonising data sources from the traditional medical model (e.g. health organisation databases) with novel big data sources, such as social media and internet query data, and wearable electronic devices, holds the potential to deliver gains in public health. Linking data from a wide variety of public sources can yield particularly powerful public health insights. For example, data from the traditional medical model can be combined with data on social determinants of health, offering new targets for personalised care and intervention.

While the majority of responding countries to a recent survey (9 of 15 OECD countries) outlined uses of electronic health information to inform public health initiatives, just three countries (Canada, Estonia, and the Netherlands) are using new, non-traditional sources of data to improve public health.

In Estonia, a large-scale clinical pilot on personalised medicine is using genomic data to target preventive care services at patients who are at risk for cardiovascular disease or breast cancer. The genetic data from more than 150 000 Estonians has been used to develop algorithms at the Estonian Genomic Centre, resulting in a clinical decision support software to help GPs detect patients at risk for cardiovascular disease or breast cancer. Over the long-term, the program intents to expand to include other preventable diseases.

In Canada, the Public Health Agency's Centre for Surveillance and Applied Research looked at how information from wearable technologies and physical activity applications ("apps") promoting healthy living can help to supplement or replace survey-based health indicators. The Centre also worked to use social media postings to inform surveillance for self-harm. While most initiatives are in the exploratory stage, a number of programs were launched to the public. Carrot Rewards, a healthy living mobile app and platform, offered participants private-sector loyalty points in exchange for healthy living behaviours, including physical activity, healthy eating, vaccinations, mental health, and reducing alcohol and tobacco consumption. More than 750 000 users participated in Carrot Rewards before the program was shut down in the summer of 2019 after filing for bankruptcy (Marotta, 2019[16]). In addition to the services provided to participants, Carrot Rewards collects user information that is shared with Canada's Public Health Agency, allowing the Agency to better target interventions to specific populations and geographic areas.

In the United States, some health insurers and care providers use comprehensive "health scores", developed by combining publicly available socioeconomic data through the *LexisNexis Socioeconomic Health Attributes Model*, to develop tailored care plans based on individual patient need. The attributes used in the model were clinically validated against claims data to confirm their predictive power and are clustered in categories such as address stability, education, and income (LexisNexis, 2019[17]). Linking big data sources in this way facilitates a better understanding of individual health risk and can thus enable improved health care personalisation, but poses data privacy concerns that must be balanced against the benefits of such an approach.

5.3.1. Novel data sources are uncommon as big data sources for public health

Recent technological advancements have led to new approaches to disease prediction and monitoring, with mixed results. Efforts have begun to systematically mine "virtual digital trails", such as social media and internet query data, to assess health-related behaviours and attitudes in near-real time. Current initiatives are promising, but most are limited to one-off projects. Moreover, where used on a wider scale this approach has delivered mixed results, with a number of high-profile failures, including Google Flu Trends, pointing to the challenges implicit in using these new data sources. Scaling up these approaches in a way that also protects data privacy and security is needed.

Infodemiology refers to systematically mining, aggregating, and analysing unstructured, textual, openly accessible online information to inform public health policy (Eysenbach, 2011[18]). *Infoveillance* refers to using infodemiology metrics for surveillance and trend analysis (Eysenbach, 2011[18]). Crowdsourcing can also be used as an alternative to infoveillance to collect public health data using big data approaches.

Social media platforms, in particular, represent sources of rich observational data for infodemiology and infoveillance (Kim, Huang and Emery, 2016[19]). For instance, in the area of non-communicable disease prevention, the dynamics of social networks can be studied to discern patterns of how social factors influence unhealthy behaviours, such as smoking (Andreu-Perez et al., 2015[20]). Furthermore, combining insights from social media data with geolocation data can enable a better understanding of patient behaviours and social demographics; it has been used to study, for instance, influenza outbreaks and antibiotic misuse (Andreu-Perez et al., 2015[20]).

Methods for collecting, filtering, and analysing social media data need to be clearly and transparently reported. As discussed further on in this chapter, data transparency is a key driver of many successful big

data initiatives, such as the "smart cities" and "smart health" initiatives. Infoveillance challenges and limitations include: privacy concerns, difficulties in establishing causal links due to lack of context, isolating signal from noise, and lack of generalisability of Internet or social media users, due to the overrepresentation of certain population groups.

Mining "virtual digital trails" – such as social media and Internet query data – offers the opportunity to assess self-reported health- related attitudes and behaviours, such as those pertaining to non-communicable diseases and their risk factors, in near real time; it can thus complement more traditional non-communicable disease surveillance data. For example, research has linked anger and stress expressed on Twitter to an increased risk of heart disease (Andreu-Perez et al., 2015[20]; Eichstaedt et al., 2015[21]). Another study was able to accurately predict the likelihood of smoking and alcohol consumption based on the user's behaviour on Facebook, including how many and what they "Liked" on the website (Kosinski, Stillwell and Graepel, 2013[22]).

Social media infoveillance can also allow public health entities to detect whether specific communities may need certain health or social services, particularly in the case of stigmatised health issues, such as drug use. This awareness can enable more targeted surveillance and enhanced interventions. For instance, one study used Twitter data to identify online communities of illicit, recreational, and medical cannabis users connected to specific dispensary accounts (Baumgartner and Peiper, 2017[23]).

"Real-life digital trails" are "signals produced by people's everyday actions, recorded digitally through devices and sensors measuring individuals' movements and behaviours" (Balicer et al., 2018[24]). The ways in which an individual interacts with digital technologies – such as through texts, calls, and social media posts – are markers of his/her "digital phenotype", which, when combined with other sources of data, such as clinical data, can allow for early disease detection and intervention (Jain et al., 2015[25]). For instance, in one study, behavioural indicators obtained from phone usage data were strongly linked to depression severity (Saeb et al., 2015[26]). Table 5.2 summarises the advantages, challenges and potential contribution to disease surveillance of sources of traditional health data, virtual digital trails and real-life digital trails.

In addition, sensor data from wearable technologies and environmental sensors can provide insights on a variety of lifestyle risk factors and aid in chronic disease management (Balicer et al., 2018[24]). Smart devices represent a promising source of crowdsourced big data that can be leveraged to track the spread of certain infectious diseases. For instance, "smart thermometers" connected to a mobile phone application provide de-identified fever data that can help track influenza activity in real time. This crowdsourced data can be used to improve influenza surveillance and forecasting by complementing traditional models, which rely on data from hospitals and clinics and which tend to lag behind real-time influenza activity. One study, which analysed data from over 8 million temperature readings generated by almost 450 000 "smart thermometers", showed that the data were highly correlated with information obtained from traditional disease surveillance systems and could potentially predict influenza activity up to two to three weeks in advance (Miller et al., 2018[27]).

The use of such smart devices is generally limited to individual purchasers who can afford to buy them, making the data susceptible to socioeconomic biases. Given the potential of these smart devices to both capture real-time infectious disease activity at a population level and help generate improved disease forecasts, policy makers should explore strategic partnerships with the private sector that could facilitate a more widespread use of such devices – provided that they have been validated against traditional surveillance methods – and a systematic integration of their data into national communicable disease surveillance systems.

Table 5.2. Big data sources: advantages, challenges, and potential contributions to non-communicable disease (NCD) surveillance

	Advantages for NCD surveillance	Challenges for NCD surveillance	Potential contribution to NCD surveillance
Health organisation databases	• Passively recorded, clinically based (credible source of clinical data) • Comprehensive EHR databases (wide range of diseases and clinical information) • Clinically representative for reporting on epidemiology, morbidity, and health service use related to NCDs • Ability to assess outcomes in relation to explanatory and risk factors • Some EHR databases contain longitudinal data with continuous membership	• Poor standardisation and harmonisation in coding and data structure pose challenges to linking and comparing data from various EHR sources • Issues of coding validity and consistency • Might not be representative of populations outside of the system • Often do not have information on behavioural risk factors, disability, and functional status	• Add breadth and depth to NCD surveillance • Ability to assess risk factors in relation to outcomes • Identify small-area variation and subgroups for intervention targeting • Flexibility to identify and respond to new or emerging problems • Identification of long-term trends • Identification of trends in health service use and correlation of utilisation with epidemiology
Virtual digital trails	• Rich, accessible, and inexpensive source of quantifiable qualitative information • Subjective, and representative of individuals' perceptions and perspectives • Some social network data offer the opportunity for technological leapfrogging and inclusion of previously excluded populations, particularly in urban settings	• Biases in who is represented, because only some segments of the population will participate • Biases in the types and accuracy of content that users are communicating publicly on social media • Dependence on changing platforms and technologies • Potential for "ecological fallacy" errors	• A situational awareness tool that can be integrated into existing surveillance frameworks as complementary data • Provide indicators of behavioural factors and functional status
Real-life digital trails	• High-resolution, real-time data • Highly sensitive to detection of abrupt changes or seasonal patterns • Some real-life digital trail data offer the opportunity for technological leapfrogging and inclusion of previously excluded populations, particularly in urban settings	• Difficult to identify the factors that cause or influence the observed trends • Sensitive to issues of individual privacy • Reliability, validity, and accuracy of these data sources for health surveillance have yet to be determined • Often proprietary data, owned by industry stakeholders • Operationalisation is contingent on data-sharing frameworks that uphold individual privacy and the competitive advantage of the data providers	• Complementary source that offers insights on new aspects of health behaviours • Can detect abrupt changes or seasonal patterns in risk factors • Information about new population segments not captured through traditional health data surveillance • Can enhance epidemiological research that monitors the association between environmental exposures and health outcomes • Additional time points and granular, local-level data

Source: Balicer et al. (2018[24]), "Using big data for non-communicable disease surveillance", http://dx.doi.org/10.1016/S2213-8587(17)30372-8.

Wearable sensors, including mobile phone accelerometers, can provide valuable data about individual behaviour and lifestyle factors, such as patterns of physical activity and sleep, which are linked to a variety of health outcomes. Combined with smart technology, the data collected by these sensors can enable personalised health promotion interventions, such as mobile phone applications that prompt a user to engage in exercise if an unhealthy pattern of physical inactivity is detected.

Data from such wearable devices, however, tends to suffer from a large amount of noise (e.g. a wrist-worn accelerometer may not be able to differentiate whether different types of arm movement indicate the user is exercising or not (Gelfand, 2019[28])). Complex statistical methods are thus needed to analyse these data. Despite these issues, wearable sensor-based interventions hold the potential to enable health policy makers to implement large-scale, highly personalised, low-cost health promotion interventions, in partnership with researchers and the private sector.

5.3.2. Big data approaches can complement traditional disease surveillance methods

Traditional infectious disease surveillance is typically based on epidemiological data collected by health institutions. While these data have a high degree of veracity, they also suffer from several disadvantages, including: time lags, due to lack of human resources or problems when aggregating data from different sources; high cost; and insufficient local granularity. In contrast, big data streams – such as internet queries, social media data, and crowdsourced data – can be tracked in real time and at a local level with minimal cost, but have their own biases that need to be accounted for. (Bansal et al., 2016[7]; Simonsen et al., 2016[29])

Communicable disease surveillance is therefore one of the most exciting opportunities created by big data in the realm of public health. These novel data streams can improve the timeliness and the spatial and temporal resolution of infectious disease tracking, as well as provide access to "hidden" populations (Bansal et al., 2016[7]; Simonsen et al., 2016[29]). Some recent successes – including Health Map's successful identification of a haemorrhagic fever outbreak in West Africa in 2014, which was subsequently identified as Ebola – point to the potential of complementing traditional surveillance methods with new approaches. Big data streams can also go beyond disease surveillance and provide information on specific behaviours and outcomes related to vaccine or drug use.

Nevertheless, while such new methods of infectious disease surveillance are promising, they may not always be mature enough and should be validated against established infectious disease surveillance systems. Policy makers and researchers must remain vigilant to avoid "big data hubris", which refers to the assumption that "big data are a substitute for, rather than a supplement to, traditional data collection and analysis" (Lazer et al., 2014[30]) – in other words, the assumption that high-volume, high-velocity data can replace smaller, high-veracity data and traditional data analysis methods (Fuller, Buote and Stanley, 2017[12]). Some past examples of big data-driven surveillance systems that suffered from big data hubris – such as, notably, Google Flu Trends (Box 5.3) – failed to deliver reliable information.

Using digital data for public health surveillance presents a set of challenges, such as: lack of demographic information; issues of representativeness, as these data tend to represent a limited segment of the population that may not include certain age categories, or may include fewer elderly individuals; and spatial and temporal uncertainty – for instance, someone may be researching a family member's illness that occurred in a different city several weeks earlier. (Bansal et al., 2016[7])

Furthermore, before relying on these types of novel data sources, public health authorities should assess the impact of local conditions on the reliability of predictive algorithms. For instance, a dengue surveillance algorithm that used Internet query data to create an index of dengue incidence worked well in areas with high incidence of dengue and favourable vector climate conditions, but was not a reliable predictor of dengue incidence in areas with low incidence and an unfavourable climate (Gluskin et al., 2014[31]).

Novel methods should therefore complement – rather than replace – traditional methods (Bansal et al., 2016[7]). Policy makers should aim for hybrid tools that combine traditional methods and big data analytics to enhance communicable disease surveillance. Hybrid tools make use of the advantages of novel big data sources – such as timeliness, scale, and fine granularity – while maintaining a direct link to disease through traditional surveillance systems (Simonsen et al., 2016[29]). Where well-performing prediction models are already in place at the national level (e.g. the CDC flu prediction model in the US), big data analytics could be used to enhance local-level data.

Box 5.3. The rise and fall of Google Flu Trends: lessons learned from a big data failure

Google Flu Trends (GFT) began functioning in 2008. The idea behind it was simple, yet revolutionary: it would monitor flu outbreaks worldwide based on Internet searches for flu-related terms. It was initially heralded as an innovative way to harness online search data to predict flu trends faster than traditional prediction systems – approximately two weeks ahead of the Centers for Disease Control and Prevention data.

In April 2009, GFT missed the onset of the non-seasonal influenza A-H1N1 pandemic, a failure attributed to changes in people's online search behaviour due to the exceptional nature of the pandemic (Cook et al., 2011[32]). Then, in February 2013, "Nature" reported that GFT was predicting more than double the proportion of influenza-like illness (ILI) doctor visits compared to the Centers for Disease Control and Prevention (CDC), whose estimates are based on surveillance reports from across the US – in spite of the fact that GFT had, in fact, been built precisely to predict CDC ILI report (Butler, 2013[33]; Lazer et al., 2014[30])

GFT likely suffered from two main problems: "big data hubris" and algorithm dynamics. "Big data hubris" refers to the "often implicit assumption that big data are a substitute for, rather than a supplement to, traditional data collection and analysis (Lazer et al., 2014[30])." Algorithm dynamics refer to the continuous modification data engineers make to the algorithm, which can cause unforeseen effects, as well as to changes in user behaviour, which can be driven by the algorithm modifications themselves.

Key lessons that can be drawn from the failure of GFT include:

- **Big data prediction models need to be transparent and replicable.** This can be achieved through collaborations between academia, public health policy makers, and the private entities that create the algorithms and own the data. Closing off the methods and data can make it difficult to validate them and rely on their predictions for decision-making (Lazer and Kennedy, 2015[34]).
- **Algorithm dynamics should be well understood and continuously analysed for potential systematic measurement errors.** This should be done particularly carefully when intentional changes are made to the algorithm for commercial purposes, and when these changes prompt changes in users' search behaviour over time.
- **Big data analytics should complement – rather than attempt to replace – traditional public health surveillance methods.** For instance, if a well-performing flu prediction model is already in place at the national level (e.g. the CDC model in the US), big data analytics can be used to enhance awareness about flu prevalence at local levels, where national data models may not be as useful. The high volume and velocity of the data should not supplant existing "smaller, slower data" if issues of reliability and measurement validity are at stake.

Source: Lazer, D. et al. (2014[30]), "The Parable of Google Flu: Traps in Big Data Analysis", http://dx.doi.org/10.1126/science.1248506, Lazer and Kennedy (2015[34]), "What We Can Learn From the Epic Failure of Google Flu Trends", https://www.wired.com/2015/10/can-learn-epic-failure-google-flu-trends/.

Participatory surveillance systems that use crowdsourcing or crowdmapping have been growing, but have yet to be used at a large-scale by public health authorities. Examples include Influenzanet – a crowdsourcing system for self-reported flu symptoms used in ten European countries, ResistanceOpen – which aggregates publicly available data on antimicrobial resistance, and Health Map – which uses online data to track infectious disease outbreaks around the world. An extension of HealthMap is "Flu Near You", which provides a crowdsourced, real-time "flu map" that shows influenza activity in the United States. As

the integration of participatory surveillance with traditional surveillance systems can significantly improve infectious disease surveillance, policy makers should explore ways in which they can develop and contribute to both national and international efforts in this area.

Surveillance systems that track infectious diseases form the backbone of communicable disease monitoring and controlling, but tend to suffer from time lags and insufficient spatial resolution. They remain primarily based on manually collected data, which is then aggregated into national or regional reports, thus lacking local-level granularity. Novel surveillance approaches that use big data streams, including electronic health (e-health) patient records, unstructured digital data sources, and participatory surveillance should be leveraged to help strengthen infectious disease surveillance systems. (Bansal et al., 2016[7])

5.3.3. Policy makers are starting to explore big data for precision public health

Precision medicine is quickly moving to the forefront of many health systems' vision for the future, driven by significant advances in genetic research. Combining traditional medical data with novel data and technologies from fields such as genomics, epigenomics, transcriptomics, proteomics, metabolomics, and phenomics is enabling a better understanding of disease pathogenesis and more targeted diagnoses and treatments, especially for cancer.

In 2016, the United States launched the USD 215 million Precision Medicine Initiative. This initiative includes, among other projects, the *All of Us* research programme, a 1-million participant study whose mission is "to accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care" by studying "individual differences in lifestyle, environment, and biology" (National Institutes of Health, 2019[35]).

While precision medicine is seen as "an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle in each person" (National Alliance Of Healthcare Purchaser Coalitions, 2018[36]), most efforts in this area have thus far focused on improving treatment, rather than prevention. The next step for health systems is to begin to use big data to transform precision medicine into precision health, by applying new insights to not only improve diagnosis and treatment, but also health promotion and disease prevention. In the United States, for example, the program *Connecting Public Health Information Systems and Health Information Exchange Organizations* gathered information on how public health jurisdictions use existing health information exchange (HIE) organizations as a means of sharing information with providers (The Office of the National Coordinator for Health Information Technology, 2017[37]).

Public health policy makers should leverage research discoveries to enable more targeted disease prevention strategies at a population level. Such prevention strategies can become an important part of "wellness planning" and health management, and a stepping stone towards providing "truly anticipatory "health care," instead of the responsive "sick care" that has long been the health care system's default" (Willard, Feinberg and Ledbetter, 2018[38])

In addition, current precision health approaches mostly focus on individual genetic variability. Most "personalised prevention" has been based on hereditary risk factors, such as cancer-causing mutations, that can be detected with genetic testing. In the United Kingdom, for example, genetic testing is made available to the family members of people with certain mutations.

In the United States, Geisinger's MyCode/ GenomeFIRST initiative provides screening for genetic variants linked to a higher risk for certain medically actionable conditions, such as the BRCA1 and BRCA2 variants associated with an increased risk of developing breast cancer (Williams et al., 2018[39]). Based on ongoing results, it is estimated that approximately 3.5% of study participants will be found to carry risky gene variants (Trivedi, 2017[40]) (Box 5.4).

Box 5.4. The Geisinger MyCode Community Health Initiative: implementing precision health by using genetic screening to prevent disease

The MyCode Community Health Initiative is a precision medicine project started by the Geisinger Health System in Pennsylvania and New Jersey. Geisinger serves approximately 4.2 million residents, with about 1.5 million unique patient visits annually. About one-third of Geisinger patients are insured by the provider-owned Geisinger Health Plan.

MyCode began in 2007 as a biorepository for discovery research, as part of Geisinger's mission to be a "learning health care system". The initiative now includes a system-wide biobank designed to store blood and other samples for research use by Geisinger and Geisinger collaborators.

Over 220 000 Geisinger patients have consented to participate in the initiative and approximately 100 000 whole exome sequences have been completed, as of August 2018. The findings are used for both research discovery (Geisinger mines DNA data and anonymised electronic health records for links between gene variants and diseases), as well as disease prevention, through the GenomeFIRST program, which was launched in 2013 as part of the MyCode initiative. If a patient-participant is found to carry one of 76 gene variants known to be causally linked to higher risk for one or more of 27 conditions, the patient-participant and their care provider are notified. Patient-participants can then opt to follow up with their primary care or specialist provider, meet with a member of Geisinger's clinical genomics team, or both. All of the 27 conditions are "medically actionable": they can be treated, managed, or prevented. Gene variants that raise the risk for certain conditions that cannot be treated or prevented, such as Alzheimer's, are not disclosed to patients-participants who carry them.

It is estimated that approximately 3.5% of study participants will be found to carry risky gene variants. What remains to be seen is whether this number is significant enough for the initiative to be cost-effective in the long run: whether the cost savings from patients who do not go on to develop the diseases for which they carry the risky gene variants will outweigh the cost of sequencing so many patients' exomes. If so, widespread genomic screening could become an important strategy for implementing precision health at a population level, particularly if the cost of genome sequencing continues to decline.

Source: Williams, M. et al. (2018[39])), "Patient-Centered Precision Health In A Learning Health Care System: Geisinger's Genomic Medicine Experience", http://dx.doi.org/10.1377/hlthaff.2017.1557, Trivedi (2017[40]), "Is health care ready for routine DNA screening? A massive new trial will find out", http://www.sciencemag.org/news/2017/10/health-care-ready-routine-dna-screening-massive-new-trial-will-find-out.

It remains to be seen whether the intervention will be cost-effective in the long run. If so, it would provide evidence that routine population level genetic screening for variants that increase the risk for medically actionable conditions should be leveraged as an important strategy for implementing precision health at a population level, particularly as the cost of genome sequencing continues to decline. Other considerations for such programs, in addition to cost effectiveness, include the potential for false positive results, as well as privacy concerns.

A precision health approach to health care, however, should move beyond just looking at genetic testing; it should take into account individual variability not only in genes, but also in environment and lifestyle, as well as their interaction. This model has been adopted by a number of large-scale research projects, including the Human Project in New York City in the United States (Box 5.5). Public-private partnerships are essential for this approach. In the United States, the State of Nevada's "Healthy Nevada Project" aims to improve population health and personalized medicine by integrating clinical, genetic and environmental data with socioeconomic determinants to better understand the interplay between these factors; for this project, health care network Renown Health has partnered with the Desert Research Institute and Helix, a personal genomics company, with support from the State of Nevada (Renown Institute for Health Innovation, 2019[41]).

Ongoing large-scale, big data-driven population studies, like the United States 1-million participants "All of Us" study and the Danish "Harnessing the Power of Big Data to Address the Societal Challenge of Ageing" research project, also hold the potential to yield valuable insights, such as identifying which types of environments are more likely to facilitate healthier behaviours.

Box 5.5. The Human Project: an atlas for the human experience

Started in 2018, the **Human Project** will use big data analytics to aggregate and analyse a variety of measurements gathered over at least 20 years from 10 000 individuals in all five boroughs of New York City. The project aims to capture the dynamic interplay of biology, behaviour, and the environment, as well as their impact on health and disease.

In addition to undergoing physical examinations, participants will need to give researchers access to medical, financial and educational records, as well as cell phone data. In total, the project will extract and aggregate approximately 50 000 data points. Participants will also receive wearable activity trackers, special scales, and surveys via smart phones. Follow-up physical examinations will be requested every three years.

The project will thus drive a better understanding of the dynamic links between behavioural phenotypes, disease, and the broader environment, as well as how human health and behaviour co-evolve over the lifecycle, and will ultimately lead to new ways of improving health promotion and disease prevention.

Source: The Human Project (2019[42]), https://www.thehumanproject.org/about/; Peltz (2017[43]) 'Human Project' study will ask 10,000 to share life's data", https://www.apnews.com/12129cb7cab542248e83c9709e2ee7d0, Santora (2017[44]), "10,000 New Yorkers. 2 Decades. A Data Trove About 'Everything.'", https://www.nytimes.com/2017/06/04/nyregion/human-project-new-york-city-study.html.

5.4. Big data can be leveraged to implement more targeted public health interventions

5.4.1. Big data approaches can help translate knowledge to practice

The development of better population profiles offers the opportunity to develop new approaches to implementing prevention strategies. Using big data to better target public health initiatives may help to improve their effectiveness. One particular area in which big data can yield valuable insights is the translation of knowledge into effective public health policy. Translation arguably represents the next frontier in public health: how to distil the vast public health knowledge yielded by public health research studies into actionable steps to inform public health policy and decision-making.

The issue of "Much is known, but little is done" is at the forefront of many countries' public health policy discussions. The European Commission, for instance, recently formalised a new mechanism, called the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases (the "Steering Group for Promotion and Prevention"), to facilitate the implementation of evidence-based best practices by EU countries to help prevent and manage non-communicable diseases (European Commission, n.d.[45]).

There are two main ways in which policy makers can leverage big data to address this issue. Firstly, big data can enable a faster, real-time monitoring of the impact of public health interventions. Changes in behaviour, public attitudes, public attention, or health status are often reflected in real-time online information sharing and communication patterns (Kim, Huang and Emery, 2016[19]). These data points can

give decision makers valuable feedback on the effectiveness of public health interventions and thus inform policy making.

Secondly, big data can facilitate a better understanding of the interaction between human behaviour/lifestyle ("behavioural phenotypes"), genetics, and the physical and social environment. Understanding which of these interactions have the greatest causal impact on public health can inform policy making – not only in public health, but also in other areas that influence health (e.g., various socioeconomic issues). Policy makers should therefore leverage big data to help move towards a Health in All Policies approach.

5.4.2. Many promising uses of big data for public health have emerged from the municipal level

In many cases, promising uses of big data for public health have emerged not from traditional public health actors, but, for instance, from initiatives to transform urban areas into "smart cities" that use data to improve urban planning, as well as policy making more generally.

As a result of accelerating urbanisation, cities face both the challenge and opportunity of being "first responders" to key global issues, including in public health, especially given many cities' status as hubs of data traffic and new technology applications. As centres for novel, big data-informed solutions and services in an increasingly decentralised world, "smart cities" have moved to the forefront of public health innovation.

Smart cities are "cities strongly founded on information and communication technologies that invest in human and social capital to improve the quality of life of their citizens by fostering economic growth, participatory governance, wise management of resources, sustainability, and efficient mobility, whilst they guarantee the privacy and security of the citizens." (Pérez-Martínez, Martínez-Ballesté and Solanas, 2013[46]). In the area of public health, smart cities can leverage their ability to develop and implement innovative, data-driven public health policies informed by big data analytics and move towards "smart health", without having to wait for national-level action – although such action can complement city-driven innovation by enhancing collaboration between cities, as discussed later in this section.

Smart health ("s-health") is "the provision of health services by using the context-aware network and sensing infrastructure of smart cities" (Solanas et al., 2014[47]). As this definition implies, ICT, big data and big data analytics are a key driver of smart health approaches.

The City of Chicago's food safety inspection, *E. coli* prediction on Lake Michigan beaches, and lead poisoning prevention programmes (Box 5.6), driven by predictive analytics and machine learning models, are examples of big data-driven, smart health solutions to public health problems. A partnership between the cities of Chicago and Las Vegas, Google, and Harvard University found that using location data and foodborne illness online searches predicted potentially unsafe restaurants better than traditional restaurant inspection methods and data-mining approaches (Sadilek et al., 2018[48]). What makes this example unique is that machine learning was used to improve accuracy, and that the linkage of these personal data also ensured that individuals remained unidentifiable.

The development and dissemination of such smart health solutions, however, has been slow. For instance, data gathered by sensors that measure environmental variables such as air pollution and airborne allergens could enhance the delivery of personalised prevention and care to asthma patients; a study that analysed data from wireless environmental sensor networks for air pollution measurement in eight cities across Europe, however, found that the performance of most of the sensors was unreliable, and they required frequent calibrations due to the interference of various environmental factors (Broday and Collaborators, 2017[49]).

Box 5.6. Chicago: Pioneering predictive analytic models for food protection and lead inspection programs

The Chicago Department of Public Health, as part of Chicago's Smart Data Project, has pioneered predictive analytics to identify the households with children most at risk for lead poisoning, as well as to more effectively monitor food establishments that are most likely to have food safety violations.

In 2014, Chicago's Department of Innovation and Technology used publicly available city data to build an algorithm to predict which restaurants were most likely to be in violation of health codes. The model aggregates data from a variety of sources (such as ZIP codes, business licenses, building code violations, and 311 complaints) to formulate a risk score, which allows inspectors to identify potential issues before they occur. The algorithm identified violations significantly earlier than business-as-usual did. Importantly, the team also made it easy for other cities to replicate Chicago's approach. More recently, the City of Chicago partnered with Google and Harvard University to test a novel machine learning-based approach that uses location data and foodborne illness online searches to predict potentially unsafe restaurants; this model is more effective than the original one (Sadilek et al., 2018[48]).

In collaboration with the University of Chicago, the Chicago Department of Public Health also developed a model that uses two decades of blood lead-level tests, home lead inspections, property value assessments, and census data to predict which households are most likely to have the greatest risk of causing lead poisoning in children. The model allows inspectors to prioritise house inspections and identify children who are at the highest risk.

An important component of Chicago's innovation strategy is liberating data: "making data accessible, discoverable, and usable by the public so that it can spur entrepreneurship, innovation, and discovery." (Choucair, Bhatt and Mansour, 2015[50]). As such, the code and data for these projects is publicly available on Chicago's "Open Source Projects" website.

The Clear Water collaborative, open source project further illustrates the data liberation approach: the City partnered with the Chicago Park District, volunteer data scientists, and local graduate students to build a better predictive model for forecasting beach water *E. coli* breakouts and help prevent infection. The model has tripled *E. coli* prediction rate on Lake Michigan beaches. The Clear Water code is publicly available and is written in R, an open source statistical programming language, which allows other scientists to test and potentially improve the current method.

Source: Choucair, B., J. Bhatt and R. Mansour (2015[50]), "A Bright Future: Innovation Transforming Public Health in Chicago", http://dx.doi.org/10.1097/PHH.0000000000000140; Sadilek et al., (2018[48]), "Machine-learned epidemiology: real-time detection of foodborne illness at scale", http://dx.doi.org/ 10.1038/s41746-018-0045-1; Spector (2016[51]), "Chicago Is Using Data to Predict Food Safety Violations. Why Aren't Other Cities?", https://www.citylab.com/solutions/2016/01/chicago-is-predicting-food-safety-violations-why-arent-other-cities/422511/; City of Chicago (2017[52]), "Clear Water", https://chicago.github.io/clear-water/; City of Chicago Developers (2017[53]), "Open source projects", http://dev.cityofchicago.org/projects/.

As noted in the Chicago case study, open data sharing represents a key driver of big data innovation and developing smart health approaches. Open data sharing helps connect smart city innovators with the relevant data. As data collection is often the most difficult part of researching and developing a solution to a particular problem, limiting data access can result in missed opportunities for "non-insiders" to develop potentially successful solutions. Open data also needs to be organized into databases with user-friendly search tools that allow easy data filtering (Smith, 2017[54]). It is also important to ensure that when data are made widely available, it is interpreted correctly by the wider set of users. Data privacy and security are, of course, particularly important when data is made publicly available.

While the cost and effort required for such projects may seem daunting, the benefits of enabling the development of innovative solutions driven by big data analytics can far outweigh these costs. Further, in the case of data crowdsourcing projects open data sharing can serve as an incentive for the public to participate in these initiatives. Examples of open data projects include La Base Adresse Nationale (France), Trafikverket (Sweden), and Data.gov (United States).

Inter-city collaboration can significantly speed up the rate of big data solutions in public health. One of the key issues of within-city innovation is that, typically, each city designs and implements its own good practices, with other cities finding out about them at a later stage, after they are successful (if ever). But co-ordination that can scale up successful solutions more effectively is needed; for instance, countries should organise partnerships between cities to facilitate tackling common issues together. Some promising examples are emerging: the Netherlands' "Smart City Strategy," for instance, aims to create a "Smart City collective" that will link cities, companies, and the research sector, functioning as a catalyst of knowledge sharing and change (Institute for Future of Living, 2017[55]).

At the same time, the important role of cities in testing and implementing "smart" approaches to public health runs the risk of exacerbating rural-urban health inequities. Policy makers should ensure rural areas are included in smart health programmes.

Another key aspect needed to advance towards smart city collaborations in the area of "smart health" are cross-sector and public-private partnerships. The "quadruple helix" collaboration between government, academia, industry, and citizens is essential for smart city and smart health innovations. Inter-sectoral collaboration is another key driver, particularly in public health, given the diversity of the causes of various diseases. As an example, Chicago's lead poisoning prevention programme involves collaboration between health care providers, lead inspectors, and housing providers, among others. Further, partnerships between cities (and other local governments) and the private sector should be explored, which can allow cities that do not yet use predictive analytics methods in-house, due to lack of resources or expertise, to contract them out.

5.5. Clear and consistent policies designed to safeguard private data are needed

Big data are increasingly allowing public health researchers and private companies to identify and link personal data across a variety of sources, many of which (e.g. smartphone data, credit card purchases, electronic medical records, GPS data) may contain sensitive health- and non-health related personal information. The implications of how this data could be used are considerable, and data protection policies that protect people from discrimination based on their health-related data is critical. While linking data that reflects health, genetic, and other personal information can provide valuable information about an individual's disease risk, it also poses the risk of uncovering potentially discriminatory personal health-related findings. (Salerno et al., 2017[56]) In addition, DNA-sequencing data can potentially be used to identify individuals by third parties.

Linking multiple data sources related to personal, socioeconomic, or other determinants of health without the individual's informed consent presents a particularly significant privacy risk, especially when the data linkage is not done for the specific purpose of answering a relevant research question or providing a clear public health benefit (Salerno et al., 2017[56]). Such data linkages, resulting in increased data dimensionality, can produce individual "data fingerprints", which can allow third parties to re-identify individuals in de-identified data sets through deductive disclosure techniques (Mooney and Pejaver, 2018[57]).

As such, wide-scale linkage of big data in public health needs to be accompanied by policies and regulations designed to safeguard privacy (e.g. sufficient de-identification of personal data), data security, confidentiality, and informed consent (Salerno et al., 2017[56]). In many cases, approaches to safeguarding privacy will require regulations that go beyond protecting health data alone and instead apply to the broader data landscape. Given

the quickly evolving nature of health data, data security and privacy risks are quickly changing, and best practices to ensure data privacy is safeguarded must be regularly assessed (OECD, 2015[58]).

5.6. Conclusion

Big data have the potential to enhance public health research, surveillance, and interventions to promote health and prevent disease, but are currently under-used. Applying big data for public health remains at a nascent stage, even when compared to other uses of data and digital technology in the health sector. However, new developments are likely to emerge in the coming years.

As emphasised throughout this report, advancing this area relies on good data governance. First, strong data governance is critical to ensure that security and privacy risks are managed – an important end as well as a key enabler of trust. Second, it promotes the development of policy and legal frameworks that enable secondary use of data in the first place. Third, it helps to maximise the utility and quality of available data (by harmonising data exchange formats enabling more data sources to be pooled, and promoting completeness of data) to generate knowledge for public health and other purposes.

Smart cities are key innovators of big data analytics solutions in public health. Inter-city collaborations can significantly speed up the development of big data-driven public health advancements. The role of cities in testing and implementing “smart” approaches to public health, however, can exacerbate rural-urban health inequities. Policy makers should ensure rural areas are included in smart health programmes. Policy makers should also leverage big data to move public health from a reactive to a predictive, precision health model.

Data transparency represents a key element that can facilitate the success of public health initiatives based on big data. Sharing data and algorithms with other stakeholders (e.g. collaborations between academia, public health departments, industry, and citizens) enables a more effective use of data and facilitates the early detection of any problems, and allows other public health authorities to implement similar successful interventions.

Despite the opportunities presented by big data, their inherent limitations and challenges suggest that their use should *complement* – not replace – traditional public health surveillance methods. Nevertheless, big data can enable a better understanding of the interaction between behaviour, genetics, and the physical and social environment. They should be put to work to generate and translate valuable knowledge into effective public health policy for better population health outcomes.

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6 Data without borders: Boosting knowledge and innovation

Jillian Oderkirk, Martin Wenzl and Luke Slawomirski

Sharing data and information across borders for the advancement of human health has taken place for a long time. With the proliferation of electronic health data, cross-border collaboration is necessary as it is increasingly clear that research breakthroughs will require large, high quality datasets that describe a range of determinants of health and disease. Challenges to cross-border collaboration and sharing of health data for research and health system performance improvement include data localisation laws and policies; data security threats that discourage data sharing; lack of global standards for data content and interoperability; and commodification and sale of health data on a world market. Some countries and institutions, such as the European Union, are making significant investments in health information infrastructure, health data governance and other steps to overcome these challenges. However, broader international collaboration is needed to coordinate and unite a global effort to address challenges.

6.1. Introduction

To meet emerging challenges of an aging population, changing disease patterns, increasingly complex health care needs and to use scarce resources efficiently, health systems need to fundamentally transform the way they use the data available to them. This Report shows that more effective use of digital technology and electronic data can help improve the delivery of health care, make health policy more effective, improve health system governance, ensure that resource allocation is based on needs and help inform citizens and patients so that they can contribute more actively to their own health and their care. Re-purposing data can also catalyse the development of new biomedical technology and allow stakeholders to unlock knowledge about the performance of technology, so that it can be used to its best effect. All of this can contribute to improving population health and achieve other policy objectives.

However, no single country should expect to have sufficient data to continue advancing medical research and scientific progress alone. The more we know about human health and disease, the more we are aware of the underlying complexity and the more specific research questions become. This increases the value of analysing datasets that are both broad and deep.

Countries already have a history of cross-border collaboration for improving health care and health. This illustrates what is possible when data are shared. With the pace of advances in digital technology, collaboration across countries to pool data and resources is becoming not only more essential but also more possible. Only cross-border collaboration can realise the potential of the unprecedented capacity for storage and processing of data for the purposes of advancing scientific knowledge, increasing the accuracy of diagnoses and the effectiveness of treatments, as well as improving policies that benefit patients and societies. The need for collaboration is already evident for rare health conditions, for complex diseases such as Alzheimer's disease, and for types of data whose size and complexity are already appreciated, such as genomic data.

The value of datasets that are pooled across national borders is greater than the sum of their constituent parts. This is because combining datasets increases sample sizes, which yield greater statistical power and increase the ability of research to detect rare events. Pooling of data also makes datasets richer, allowing comparative research to explore the reasons for variation between sub-groups of populations, regardless of how these are defined and stratified. For example, breast cancer is no longer considered a single condition but rather a category with more than a dozen forms, each differing from the others by genetic and hormonal factors that will respond differently to treatment options. In addition, larger-scale collaboration allows for a more concerted approach to ensuring data security and can provide greater resilience against increasingly globalised security threats.

Data therefore need to be freed up for use and re-use not only within, but also across countries. However, it is not sufficient to only make data accessible. For data to support research and the advancement of knowledge effectively, they also have to be valid and comparable, requiring adherence to shared data standards and definitions. Finally, sharing of data across borders also requires collaboration in data governance, to ensure that people's privacy is protected. International collaboration is essential to manage the security risks associated with growing data commodification and evolving technology. A collective effort, and the sharing of knowledge and technology, are far more effective and efficient than a bespoke approach within jurisdictions.

This chapter examines the history of cross-border collaboration for the improvement of health and health care and biomedical research and innovation. The focus is on the regions of the world where cross-border projects are taking place, primarily within Europe and among a small sub-set of countries outside of Europe. The Chapter discusses recent investments by governments in health information and research infrastructure for cross-country collaborative work, and the policy environment for cross-border data exchange. It discusses the main challenges countries are currently grappling with, such as data localisation, security risks, data commoditisation and interoperability. Finally, the Chapter concludes with

making a case for harmonisation toward a common health data governance framework and shared health data standards. The final section also outlines next steps supporting cross-country collaboration for improved health care quality, performance and research and innovation.

6.2. Cross-border collaboration using health data has a rich and fruitful history

The possibility – and the benefits – of sharing data, information and knowledge across jurisdictions for the advancement of human health have been demonstrated for a long time. The scope ranges from sharing general health system information to specific clinical areas, most notably cancer. Multi-country collaboration has yielded strong dividends. Consequently, institutions such as the European Union are working toward a common health information infrastructure across its member states.

6.2.1. International sharing and use of data have promoted learning and improvement

High quality, comparable data and statistics enable continued advancement in the biological sciences, support public transparency about health and health care, identify areas for policy action and support policy evaluation. They are essential for research as well as good governance. The OECD, the World Health Organisation (WHO), the World Bank and other international organisations have, for decades, compared health and health care across the regions of the world. The breadth of the investments in harmonising global health-related data is too wide to document here, but a few examples illustrate the priority governments and health system leaders place in this vital work.

- Comparable health data published by the OECD contribute to regularly published indicators of health status, health risk factors, health service utilisation, health care quality, pharmaceutical markets, and health expenditures and financing (OECD, 2019[1])
- WHO Global Health Observatory publishes annual comparable statistics on a wide range of topics related to the health status of populations, including communicable diseases, non-communicable diseases and injuries, immunisation, health personnel, reproductive health, health risk behaviours and environmental health risks (WHO, 2019[2]).
- The Institute for Health Metrics and Evaluation (IHME), an independent global health research organisation, publishes the Global Burden of Disease periodically to report on the state of health in countries and world regions regarding mortality and disability from diseases, injuries and health risk factors (IHME, 2019[3]).
- The World Bank publishes annual statistics on health and nutrition for countries across the world that contribute to monitoring poverty reduction, including indicators of communicable diseases, non-communicable diseases and injuries, reproductive health, health status, health risk factors, immunisation, health service use and health expenditures (WorldBank, 2019[4]).
- The Commonwealth Fund, a private foundation in the United States, conducts surveys and publishes comparable indicators to support health system performance. It regularly surveys adults and older adults in multiple countries regarding health care utilisation, experiences and outcomes and it has surveyed primary care physicians in multiple countries about care coordination and preparedness to care for key patient populations (CWF, 2019[5]).

6.2.2. International reporting of cancer indicators began 50 years ago

Perhaps in no other disease area have countries invested and benefited from cross-country collaboration more than in cancer. Here, international measurement and reporting has existed for over 50 years.

The International Agency for Research on Cancer (IARC) was launched in 1965 and publishes comparable indicators of cancer incidence and mortality (IARC, 2019[6]). In 2012, the IARC Global Cancer Observatory

provided incidence, mortality and prevalence indicators for major cancer types from cancer registry data within 184 countries (IARC, 2019[7]). The IARC also has a biobank holding biological samples from 560 000 individuals. The majority of these are from the European Prospective Investigation into Cancer and Nutrition (EPIC), which collected biological samples as well as diet and lifestyle factors from 370 000 people in 10 European Countries from 1992 to 1999.

The CONCORD project has expanded the global surveillance of cancer to estimates of survival. The project comprises a series of global studies. The third study involved 71 countries over the period 2000 to 2014, presenting indicators of five-year net survival for 18 cancer groupings representing about 75% of all cancers (CONCORD, 2019[8]).

Several efforts in Europe are developing indicators related to cancer. These include the European Cancer Information System (ECIS) providing indicators of cancer incidence, mortality and survival, and the EUROCARE study which provides indicators of five-year relative survival (ECIS, 2019[9]) (EUROCARE, 2019[10]). The RARECAREnet study, using data from EUROCARE-5, reported comparable indicators of cancer incidence, prevalence and survival of rare types of cancer (RARECARENET, 2019[11]).

6.2.3. Multi-country collaborations have yielded dividends

In 2005, the Nordic Council of Ministers, including Denmark, Finland, Iceland, Norway and Sweden, established NordForsk to strengthen Nordic research across scientific domains including a Nordic Programme on Health and Welfare (NordForsk, 2019[12]). The Programme aims to increase public health and welfare in the Nordic countries through multi-disciplinary research. The collaboration supports competitive applications from Nordic researchers for European scientific advancement.

All of this is underpinned by investment in high quality information infrastructure, including the harmonisation of the population-based registries and biobanks of the participating countries to enable their data to be linked for analysis.

By pooling their nations' data, researchers from Nordic countries have benefitted from larger sample sizes. Examples include using data from Denmark, Norway Sweden (and the Haute-Garonne district in France) to study the effects of exposure to antiviral drugs used to prevent and treat influenza during pregnancy on neonatal outcomes and congenital malformations (Graner et al., 2017[13]). Pooling of data was essential to achieve a sample of 5 800 patients over a two-year period.

Another example involved pooling data from health registries in Demark, Finland, Norway and Sweden with data from the UK Clinical Practice Research Datalink to create a multi-national sample to study cancer incidence among new insulin users (But et al., 2017[14]). Data pooling resulted in 21 000 cases of cancer that could be studied over a follow-up period of about 5 years and enabled examining risk of developing ten types of cancer.

Data from registries in Denmark, Finland, Iceland, Norway and Sweden were combined to study the effects of anti-depressant medications in early pregnancy on birth defects (Furu et al., 2015[15]). The study used data from 1996 to 2010 that yielded over 36 000 live births to women exposed to the medications. Among these births were a cohort of 2 800 siblings where one birth involved exposure to the medication and the other did not. The sibling cohort enabled examination of the potential influence of lifestyle and familial factors on the results.

Australia and Canada collaborated to produce comparable profiles of opioid use and harms in both countries. The goals of the collaboration were to learn about the differences and similarities between the countries through the exploration of five different types of opioid harm: accidental and intentional poisoning, opioid dependence, adverse reaction to opioids and other types of harm. The project was a parallel study, with analysts in each country aiming to follow common methods and share findings (AIHW, 2018[16]; CIHI, 2018[17]).

6.2.4. Global projects are establishing an international research infrastructure

The global biomedical research community has been making progress in promoting the cross-border exchange of health data for scientific research. While it is impossible to describe all of the global bio-medical research initiatives here, the following examples from the fields of genomic research, rare disease research and brain research illustrate the breadth and focus of this work.

The largest internationally collaborative bio-medical research project was the Human Genome Project (NIH, 2019[18]). Led by the US National Institutes of Health (NIH), the project plan was released in 1990 and by 2003 the project had published the full human genome sequence. The sequence constitutes the instructions for the development and functioning of a human being and forms the basis upon which we can explore genetic factors leading to health and to disease. The genetic data used in the study came from a small number of consenting individuals whose identities have been protected. The sequencing of the genome was conducted at numerous universities and research centres throughout the United States, the United Kingdom, France, Germany, Japan and China.

The International Rare Diseases Research Collaboration has established Taskforces to promote the sharing of and management of data across borders in a range of intersecting areas: developing data terminology standards, fostering the sharing of data mining tools, automating accessibility of patient consent information across datasets and creating model patient consent clauses that are valid across jurisdictions. A joint Taskforce with the Global Alliance for Genomics and Health (GA4GH) is developing a policy for participant-specific identifiers that enable the linkage of datasets while protecting data subjects' identities (IRDIRC, 2019[19]).

Research into the brain is an area where global collaboration to share data and infrastructure is particularly important. Understanding brain function and disease is highly complex and many countries have made large investments in brain research, which could be made more efficient and more productive with greater collaboration. The International Neuro-informatics Coordinating Facility (INCF) supports brain research through the promotion of neuro-informatics and by advancing data reuse and reproducibility, two areas that have been recognised as needing improvement (INCF, 2019[20]). INCF collaborates with the International Brain Initiative, which is developing closer ties among brain research initiatives in Europe and in countries including Australia, Japan, Korea, Israel, and the United States. The aim is to promote research collaboration, data sharing and sharing of research infrastructure (Yuste and Bargmann, 2017[21]). The INCF also collaborates with the *Neurodata Without Borders* Initiative which focuses on international standardisation of neuroscience data and removing obstacles to data exchange (NWB, 2019[22]).

6.2.5. The European Union is developing a common health data infrastructure to promote data sharing across member states

The EU is making significant investments in elements of a pan-European information infrastructure to drive better biomedical research, health system surveillance and clinical information exchange, and improve patients' access to quality care and their care experience. Work is underway in areas such as data infrastructure for health system performance monitoring and research, infrastructure for clinician collaboration in patient treatment decisions and research, and data and infrastructure for biomedical and genomic research.

Ensuring data quality and accessibility to advance shared policy objectives

A Joint Action on Health Information (InfAct) was launched in 2018, aiming to consolidate and progress previous EU investments to develop a sustainable health information infrastructure: the European Research Infrastructure Consortium (ERIC) on Health Information. The goal is to generate policy-relevant knowledge regarding health and health system performance (INFACT, 2019[23]). The Joint Action includes twenty-nine participating countries that work toward addressing challenges in the variability of health

information quality, completeness, accessibility and comparability across countries and to improve health information governance and sustainability. InfAct aims to:

- prioritise addressing information inequalities across countries;
- improve the education and training of data analysts;
- develop a web-based health information platform (ECHI);
- develop health and health care quality indicators involving the linkage and merging of data related to health care reimbursement, hospitalisations, deaths and health and health examination survey data;
- develop a business case for ERIC; and map progress in health information interoperability, both in terms of technical interoperability and the legal and policy framework for health data governance.

InfAct builds on the EU-Bridge project (2015 to 2017), which consolidated several initiatives that aimed to improve health information infrastructure to enable *inter alia* population health and health system monitoring, indicator development, assessing environmental impact on health, disease registries, and clinical and administrative health data collection systems. The EU-Bridge Project demonstrated the value of multi-country research involving the linkage of hospital data to other health care datasets across the health care pathway and the pooling of hospital datasets to enable new insights about the quality and efficiency of care (Häkkinen et al., 2013[24]) (ECHO, 2013[25]).

The EU-funded CEPHOS Link project applied a common protocol to administrative data from national health care databases in six European countries (Austria, Finland, Italy, Norway, Romania, Slovenia) – all with different health care systems and varying data collection methods – to estimate psychiatric rehospitalisation rates and their predictors (Katschnig et al., 2017[26]). The project involved data acquisition, management, quality, interoperability, privacy protection and linkage methods and included local and pooled data analyses, performed with statistical methods and innovative dynamic modelling approaches.

Improving access to information for clinicians is also a priority. European Reference Networks (ERN) link health care providers in European countries, supporting them to treat patients with rare or low-prevalence complex diseases (Commission, 2019[27]). The ERN provides an ICT platform and telemedicine tools for virtual conferencing of health care providers across Europe to provide advice to a health care provider on the treatment of their consenting patient. There are 24 ERNs covering a range of disease conditions and involving specialised care units in 300 hospitals in 26 countries. Beyond supporting diagnosis and treatment decisions, ERNs aim to facilitate large-scale clinical studies of patients supporting research into new medicines, medical devices, health care models and e-Health solutions.

The EU is developing digital infrastructure for the cross-border exchange of health data. The eHealth Digital Service Infrastructure (eHDSI or eHealth DSI) facilitates data exchange among countries and includes services to exchange patient summaries and ePrescriptions (EU, 2019[28]).The aim is that by 2021, these exchange services will be available in over twenty EU countries (European Commission, 2019[29])

Large pan-European datasets are developed to bolster biomedical research

It is becoming clear that breakthroughs in biomedical research will increasingly rely on using large, high-quality datasets that describe a range of determinants of health and disease. Datasets of sufficient size can only be created by cross-border collaboration. Indeed, private pharmaceutical studies are often multi-country.

The European Union is taking steps to create an enabling infrastructure and environment. A number of European initiatives are underway to enable better research using the human genome (Box 6.1). In particular, the EU is developing a large prospective cohort of data on 10 million people by 2025 to promote research and innovation in precision medicine at the EU level. This project involves a commitment from twenty-one countries to sharing genomic and clinical data across borders.

Box 6.1. Initiatives to power up bio-medical research in the European Union

The EU is aiming for 1 million sequenced genomes by 2022 and to develop a large prospective cohort of 10 million people by 2025 (including molecular profiling, lifestyle, genomics, environment and linkage to electronic health records (EHRs)). The goal is to promote research and innovation in precision medicine and treatments for rare diseases, cancer, brain function and disease prevention on a European level. Since launching the 1+ Million Genomes Initiative in September 2018, 21 countries have signed the declaration and agreed to cooperate in sharing genomic data across borders (Commission, 2019[30]). Success in this ambitious initiative will rely on a technical infrastructure throughout the Union that:

- enables secure, federated access to genomic data;
- ensures that legal requirements for data protection and ethical implications of research are clear and taken into account;
- keeps the public and policy makers updated about progress in genomics; and
- ensures that results are translated into improved care.

The EU is also developing a resource for European-wide and multi-country research involving human biological samples and bio-molecular resources and associated clinical and research data referred to as BBMRI-ERIC (Biobanking and Biomolecular Resources Research Infrastructure – European Research Infrastructure Consortium) (BBMRI-ERIC, 2019[31]). BBMRI-ERIC aims to provide expertise and services to its members to facilitate access to the resources and collections of members. Seventeen countries, most with multiple participating biobanks, are participating: Austria, Belgium, Bulgaria, Czech Republic, Estonia, Finland, France, Germany, Greece, Italy, Latvia, Malta, Netherlands, Norway, Poland, Sweden and United Kingdom.

The Adopt BBMRI-ERIC project, supported by an EU Horizon 2020 grant, fosters participation in BBMRI-ERIC and includes a demonstration case study to develop a research infrastructure for colorectal cancer (BBMRI-ERIC, 2019[32]). The study aims to collect 10 000 colorectal cancer datasets from twelve countries for research to improve the treatment of this disease. The colorectal cancer research dataset will become a permanent asset of BBMRI-ERIC. Datasets for research into other chronic conditions are envisaged and the procedures and IT tools developed for the colorectal cancer cohort aim to be re-useable for the study of other diseases.

ELIXIR is a European Intergovernmental Organisation involving 20 countries that is helping them to manage the huge increase in life sciences data, particularly data related to DNA and RNA sequencing (ELIXIR, 2019[33]). The life sciences data includes data for humans, as well as other organisms. ELIXIR offers a computer platform that is a network of supercomputing services to improve storing, transferring and analysing huge datasets. A data platform provides markers of dataset quality and an interoperability platform is standardising the way data are saved and described. ELIXIR provides researchers with tools and training to work with large and complex datasets.

The European Human Biomonitoring Initiative (HBM4EU) aims to harmonise procedures across countries to enable more comparable data on human exposure to chemical substances to coordinate and advance human biomonitoring in Europe (HBM4EU, 2019[34]). The project involves 28 countries, the European Environment Agency and the European Commission and is co-funded under Horizon 2020 from 2017 to 2021. The project also aims to explore the link between external exposure to chemicals via multiple routes and the aggregate internal exposure within individuals and the health outcomes associated with exposure.

6.3. Key challenges concern data localisation, security, commoditisation and interoperability

The major challenges to cross-border collaboration and sharing of health data for purposes such as research and health system performance can be distilled to four categories:

1. data localisation laws and policies;
2. data security threats that discourage data sharing;
3. lack of global standards for data content and interoperability; and
4. commodification and sale of health data on a world market.

This fourth challenge of data commodification, or a health data 'gold rush', is in many ways a direct result of the first three. Many countries have laws and policies that prevent health data from being shared for multi-country research and these restrictions are at least partly due to concerns about data security protections for multi-country studies. Even among countries where data can be shared for multi-country studies, the data are not standardised to consistent global standards for content or exchange. As a result, private-sector actors that acquire treasure troves of patient health data can develop profitable businesses cleaning and prepping data for research use and then licensing access to them. This emergence of health data vendors raises ethical concerns and calls for a globally coordinated response.

6.3.1. Data localisation laws and policies can limit cross-border sharing

Many countries are still in the process of developing national health data governance frameworks that enable data within the country to be amalgamated, linked and analysed and include mechanisms for national researchers to access data securely but also practicably. While these initiatives are important priorities, countries developing such frameworks should consider whether existing or planned legislations and policies may, expressly or inadvertently, entrench data localisation – a major barrier to cross-border collaboration.

In some OECD countries, data localisation regimes either explicitly forbid health data processors from approving the sharing of data with an organisation located outside of their country or create obstacles such as a lack of clarity about how data sharing outside of the border might be approved. Existing regimes can also result in processes to obtain approval that would be prohibitive in terms of time and resources. In federated countries, laws and policies within states, provinces or regions may entrench data localisation at a national level.

In a 2019 OECD survey on health data governance, countries were asked if de-identified data from ten key national health datasets may be shared with approved researchers working in a foreign academic or non-profit research organisation. All datasets examined were national in scope and contained personal data (i.e. records of individuals). Seven countries, Australia, Belgium, Canada, Denmark, Norway, Singapore and Slovenia, reported that de-identified data could be shared from six or more key national health datasets for approved research work (Table 6.1).

Australia noted that while such sharing is possible, no instances of such sharing are known in practice. Australian researchers who demonstrate that their work has been approved by the appropriate ethics committee should be able to access de-identified data securely. However, approval processes can be complex and lengthy in order to ensure that the use of the data would be secure and appropriate. This may be a barrier to accessing and using these data.

Canada reported that such sharing is possible at the national level but only if it is not prohibited by provincial law or by the terms of data sharing agreements with data suppliers. Germany also indicated that due to a federal structure, state data protection laws and laws governing hospitals may prohibit data sharing with foreign entities within, and outside of, national borders.[1] This illustrates how the harmonisation of policy frameworks within countries is critical.

Table 6.1. Foreign academic and non-profit researchers may be approved access to de-identified personal health in some countries

Potential for access approval for 10 national personal health datasets, by country, 2019

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data
Australia	Yes[1]	Yes[1]	Yes[1]	Yes[1]	Yes[1]	Yes[1]	Yes[1]	n.a.	Yes[1]	Yes[1]
Belgium	Yes	Yes	Yes	Yes	Yes[2]	Yes	Yes	n.a.	n.a.	n.a.
Canada	Yes[3]	Yes[3]	Yes[3]	n.r.	No	Yes	n.a.	n.a.	Yes	Yes[3]
Czech Republic	No	No	No	n.a.	No	No	No	No	No	n.a.
Denmark[5]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.
Germany	Yes	n.a.	n.a.	n.a.	No	Yes	n.a.	n.a.	n.a.	n.a.
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.
Israel	No	No	No	No	n.a.	No	No	n.a.	No	No
Japan	No	No	No	No	No	No	n.a.	n.a.	No	No
Korea	No	No	No	No	No	No	No	n.a.	No	No
Latvia	No	No	No	No	No	Yes	Yes	n.a.	Yes	n.a.
Luxembourg	Yes[4]	Yes[4]	n.a.	No	No	Yes	n.a.	n.a.	Yes	No
Netherlands	d.k.	d.k.	n.r.	Yes	d.k.	Yes	n.a.	n.r.	Yes	Yes
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.
Sweden	No	No	No	No	No	No	No	No	No	No
United Kingdom (Scotland)	No	No	No	No	No	No	No	n.a.	No	No

n.a. Not Applicable; n.r. Not Reported; d.k. Unknown
1. Potentially but we are unaware of any cases.
2. Data without risk of re-identification.
3. Except where prohibited by law or agreement.
4. Only the dataset of the National Health Insurance and the Directorate of Health may be shared.
5. Researchers not based in Denmark may obtain access to data from the national health registries provided they collaborate with a Danish research and analysis environment
Source: OECD (2019[35]), "Survey on health data governance: preliminary results".

Cancer registry data are the national data that are the most likely to be shared internationally. Eleven of eighteen countries reported that they could share de-identified national cancer registry data with approved foreign researchers in academic and non-profit organisations. Along with the rich history of international cancer research collaboration (outlined earlier), this reflects the success of creating a policy and legislative environment that enables relevant data to be available for research. It also illustrates that it is eminently possible to free up personal health data for secondary uses with the requisite political will and coordination of effort.

In some countries, however, no key national health data can be shared. Five countries, the Czech Republic, Ireland, Korea, Sweden and the United Kingdom (Scotland), would not approve sharing de-identified data from any of the thirteen key national health datasets with a *foreign* researcher in the academic or non-profit sectors. Privacy policies in Israel limit approval of data sharing outside of the country, but mechanisms exist to permit sharing under agreed conditions. The preference is to provide access to information.

Under the European General Data Protection Regulation (GDPR), which entered into force on 25 May 2018 and protects the personal data of residents of the European Economic Area (EEA), de-identified microdata may still be considered personal data and be subject to the same levels of protection. Ensuring that GDPR requirements are met was noted in the 2019 survey as a barrier to data sharing by Germany and the Netherlands. Belgium reported that the lack of a policy on health data sharing with foreign non-profit researchers is a barrier.

6.3.2. Emerging technologies pose data security threats that call for collaborating on innovative solutions

Health care data have a high economic value (see Section 6.3.3), raising the risk of security breaches and attacks. Concerns about data breach and re-identification risks limit health data sharing within and across borders due to concerns with preserving data security when data are, for example, uploaded to a cloud. While the concerns are certainly legitimate and need to be managed proactively, they need to be approached in the context of the benefits foregone by prohibiting secondary uses of personal health data,

Nevertheless, an environment that aims to foster cross-border projects requires on-going international collaboration to develop shared approaches to data security protection that prevent and address emerging threats. While emerging threats related to technological advancement could harm individual countries whether they engage in multi-country collaborative projects or not, the desire to collaborate should stimulate joint investment and collaboration in threat detection and response.

A United States-based law firm providing global services annually compiles information on data security among the clients that it represents, shedding light on data security threats (BakerHostetler, 2019[36]). The firm reported involvement with over 750 data breaches in 2018, 25% of which were within health care organisations including pharmaceutical and biotechnology companies. The most common types of breach were phishing attacks (37%) and network security hacks (30%). Phishing attacks most often involved an email or message that tricked individuals into providing log-in information then used to access the data. Network intrusions occurred most often when servers were internet accessible and unsecured and when devices with file transfer protocols or remote desktops were unsecured. Other reasons for data breaches included inadvertent disclosure (12%), lost or stolen records and devices (10%) and system misconfiguration (4%).

While these data security challenges are already daunting, new risks are appearing on the horizon. For example, any scaling up in the availability and use of quantum computers enables breaking the public key cryptography that the world uses now for data security for secure banking transactions, websites and web transactions (see Section 6.4.3).

6.3.3. The data 'gold rush' raises ethical concerns

The monetisation of health data by private sector actors is an area of ethical concern and is increasingly global in scope. Private firms develop or acquire access to patients' health care data through acquisition of health care organisations or electronic medical record (EMR) software providers. Becoming the health care data custodian, firms may use the data directly for development of products or monetise the data by licensing access to other users, such as pharmaceutical companies and software applications developers. Often the data involved are from records created through publicly-funded service provision, and yet somehow become privately held goods.

For example, one of the most long-standing health data vendors was IMS Health, a United States-based company that bought data about individual patients from pharmacies, EMR software systems, and health insurance providers. IMS merged with Quintiles in 2016 to form IQVIA. IQVIA indicates that it can provide clients with access to data on 600 million patients from 100 countries from sources as wide ranging as EMRs, insurance claims, pharmacies, labs, medical images, genomics datasets, and social media (IQVIA, 2019[37]).

Flat Iron Health provides an illustrative example of how a private company can access and sell patient data. Flat Iron Health is an oncology focussed EMR software vendor based in the United States. Through the software, Flat Iron accesses patients' medical data from health care providers and administrators within 200 Cancer Centres (Flat Iron Health, 2019[38]; Forbes, 2018[39]). Flat Iron data customers are pharmaceutical companies who purchase licences to access the data. Roche Pharmaceuticals acquired Flat Iron in 2018 and will access the data to identify and recruit patients to clinical trials and to facilitate access to clinical data for trial participants (Forbes, 2018[40]).

IBM has also acquired a considerable trove of patient data through acquisitions of companies in the custody of data. For example, it purchased Truven Health in 2016, adding 200 million patient records to its holdings of 100 million records (Fortune, 2016[41]). Truven offered health care data management and analytics services and reported over 8500 clients including hospitals, insurance companies and data from US and state agencies.

Patient-level health data have thus been commodified and present attractive potential profits. Unsurprisingly, technology companies, such as Google, Amazon, Microsoft, Apple and Facebook, have announced significant investments and acquisitions to gain access to health data. These range from offering smartphone Apps for people to aggregate and store their patient records, to offering health care to employees and mining their data, to acquiring and investing in health data aggregators, health social media and genomics companies, to artificial intelligence and data mining services (Computer World, 2019[42]; Businesswire, 2018[43]; Healthcare Weekly, 2019[44]).

The commodification of data raises concerns. These include whether patients' legal rights regarding the use and management of their data are adequate and enforceable, whether data generated from public investment in health care provision are serving the public interest when they are commodified and sold to those who can afford it. Another question concerns whether trust in governments and health care providers will be eroded by the commercialisation of patients' personal data.

6.3.4. Lack of common standards and interoperability raises risks and limits potential for collaboration

A contributing factor towards this health data gold rush is the lack of standards for health data content and data exchange, although there is work in progress on public data standards (see Section 6.4.2). This situation has created opportunities for firms to clean, harmonise and link data to produce proprietary patient-level information suitable for clinical research. With shared global standards (or mapping to shared standards) data could be more easily brought together within and among countries for approved initiatives.

The lack of common data terminology and exchange standards also creates barriers to and inefficiencies in sharing and diffusing data-driven technologies, such as software tools, apps and algorithms, among health care organisations within countries and certainly across countries.

Effectively, the bespoke approach that has often been taken to health data development causes health organisations, systems and countries to continually re-invent the wheel and is a major barrier to applying data toward modernising health care organisations, advancing research and personalising and improving health care experiences for patients.

Standards developed by the World Health Organisation have so far been diffused most widely. The WHO has, for example, developed and diffused the global standard for diagnosis coding, the International Classification of Diseases (ICD), since the creation of the WHO in 1948. The eleventh revision of this standard was developed to better suit digital health records and it will be used for national and international reporting beginning in 2022 (WHO, 2019[45]). The WHO is developing an International Classification of Health Interventions (ICHI) that will include interventions across a wide spectrum of health care including diagnostic, medical, surgical, mental health, primary care, allied health, functioning support and public health interventions (WHO, 2019[46]). The WHO also maintains the International Classification of

Functioning, Disability and Health (ICF) which measures health and disability (WHO, 2019[47]) and the Anatomical Therapeutic Chemical (ATC) classification for coding of medicines (WHO, 2019[48]).

Medical terminologies that complement the WHO family of classifications are also emerging. For example, SNOMED CT codifies health and care issues with a high level of detail and enables exchange of data and subsequent cross-border research, using data entered as part of the primary workflow in health and care services. Medical terminologies are complementary to the WHO classifications in their potential to identify conditions that normally would be coded as "Not elsewhere classified" or "Not elsewhere specified". This is an important feature supporting the research use of data, particularly clinical research.

Another characteristic of SNOMED CT is its underlying ontology. An ontology means that each clinical idea has a set of relations that can be used for analytics. Big Data analytics can use these relations and other mechanisms for data mining and other forms of analytics. SNOMED CT is developed and licensed by SNOMED International, a not-for-profit organization owned by its members.

However, alignment to common data standards is weak among OECD countries as has been shown in a 2016 study of electronic health system development, data use and governance (Oderkirk, 2017[49]). In 2016, countries reported variable use of WHO and other global data standards for key elements within electronic clinical records. Further, twenty countries reported that the data content standards used differed among regions and health care organisations within their countries.

Global standards are also lacking for important elements within clinical records, such as standards for contextual information for patients about demographic and socio-economic characteristics, health and risk behaviours, family history and community support, and patient preferences and experiences – all of which are increasingly relevant data in the context of changing epidemiological trends. Standards and methods are further needed to extract key information for research uses from data that are left uncoded in text-based clinical notes inside patients' records.

6.4. Strong governance, common data standards and a collaborative approach to data security is needed

The benefits and opportunities of sharing health data across borders in advancing global health and health system performance are clear. However, a number of technical and policy challenges stand in the way of enabling a productive global ecosystem for health data. Overcoming these challenges requires a co-ordinated global effort to set the right policy, governance and regulatory frameworks within and across countries. The key factors are ensuring common data standards and exchange formats that enable efficient sharing of various types of health data, and working together to maximise the security of personal health data and minimise the risks of privacy breaches in the face of constantly evolving threats. All of this can be achieved and a number of noteworthy initiatives are under way. But greater global co-operation is needed.

*6.4.1. **Appropriate regulations enable the secure and productive sharing of health data across borders***

Strong governance and regulation are now accepted as foundational requirements to putting data to work – within and between countries – in a secure and ethical way. The EU is the most advanced region to promote the sharing of health data across national borders while continuing to protect privacy. The aforementioned European GDPR places personal health data in a special category with the highest standards of protection. Compliance requires that personal health data are very well organised and portable (EU, 2019[50]). For example, organisations must have data systems that allow them to fulfil individuals' rights to access their own personal data, to rectify or restrict their processing, and to request data portability from one organisation to another; as well as to assure data are correctly categorised and to demonstrate compliance with the regulation.

Several positive consequences of the GDPR include that health data systems will become more digitised, more useable, harmonised from one country to another, more accessible to patients and better secured. Thus, there is a potential that this better data would foster EU-wide research and statistics. A more harmonised approach to data protection within the EEA through the GDPR will enhance EU-wide collaboration in health information development and use.

The GDPR also sets out clear requirements for the sharing of data between members of the EEA and non-EEA countries and international organisations. Such sharing is possible where the non-EEA country or international organisation provides a level of data protection that is considered adequate vis-à-vis the protection provided under the GDPR. Countries are further supported in determining adequacy through guidelines being developed by the European Data Protection Board (EDPB), which includes representatives from the data protection authorities of each EU/EEA member state (EU, 2019[51]).

Importantly, the EU has also established a policy framework to support the sharing of health data across borders. This includes work toward a fully interoperable EHRs for diagnosis, treatment as well as research and disease prevention, and policies promoting effective sharing of genomic datasets to advance scientific discovery and precision medicine (EU, 2019[52]). For example, the EU is aligning health data sharing with investments in high performance computing and an open science cloud to develop predictive approaches to treatment based on simulation and AI.

Beyond Europe, the aforementioned GA4GH is developing policy frameworks and technical standards to enable cross-country research projects involving the sharing of genomic and clinical data within a human rights framework, which ensures research ethics, data privacy protection, regulatory compliance and data security (GA4GH, 2019[53]). GA4GH has a current initiative providing information briefs for understanding and meeting the requirements of the EU Data Protection Regulation. Members of GA4GH include universities, hospitals, health care organisations, research institutes, and life sciences and IT companies within 71 countries.

At the country level, the United Kingdom has made progress to improve the sharing and use of health data among its countries (England, Scotland, Wales and Northern Ireland), through initiatives led by the Farr Institute and, more recently, Health Data Research UK (HDRUK, 2019[54]). Both projects promote collaboration among UK countries for secure analysis of health care, genomic, clinical and biological data by identifying and removing obstacles to collaboration in health data projects due to unnecessary differences in health data governance, such as cumbersome approval processes and data access mechanisms. The Health Data Research UK project supports UK members in engaging in joint research in artificial intelligence with the Alan Turing Institute in order to achieve breakthroughs in the diagnosis of chronic diseases.

Governments need to develop the right legal and regulatory frameworks that protect individuals and the public interest

Concerns regarding individual rights to privacy and the growing commodification of health data were outlined above. These need to be managed in a proactive and transparent manner through strong regulation and governance. The EU GDPR offers strong protection for personal health data. Under the GDPR, patient data where direct identifiers have been removed, such as names and health and social insurance numbers, may still be considered personal health data and be subject to protection. This could allow patients in EU countries to exercise rights over their personal data held by private companies, such as rights to access, rectify and restrict data uses. Further, the GDPR would limit data uses to those authorised by patient consent or by law.

Other privacy law in OECD countries may exempt data that has been de-identified from legal protection, and it is in those situations that patient-level data is most easily commodified and marketed.

However, provisions of all privacy law permit data uses with patient consent which raises issues of the adequacy of the consent process. For example, patients may have little alternative to consenting to third party uses of data, when consent is a prerequisite for accessing a needed product or service. This includes participation in social media platforms, accessing smartphone apps to acquire and share your own electronic medical records, genetic analysis of ancestry, lowering insurance premiums by using health monitoring devices, or accessing better or lower cost health care provider through an employer.

The onus is on governments to take stock of the risks and opportunities of secondary data use (within and across borders), and develop the legal and regulatory frameworks as well as incentives to protect individuals while allowing innovation and the development of new treatments and services in the public interest. As the risks are increasingly global in scope, it is increasingly necessary to harmonise toward common legal frameworks and standards.

The OECD Council Recommendation on Health Data Governance sets out the framework conditions within which countries can harmonise toward a more common approaches to both protecting health data privacy and advancing health policy objectives by fostering research and evidence (OECD, 2019[55]).

The Recommendation calls on countries to support cross-border collaboration in the processing of personal health data for health system management, research, statistics and other health-related purposes that serve the public interest. This includes identifying and removing barriers to effective cross-border collaboration in the processing of personal health data; and facilitating the compatibility and interoperability of health data governance frameworks so that cross-country collaboration is possible. It also includes a call for governments to engage with relevant experts and organisations to developing mechanisms to enable the efficient exchange and interoperability of health data including setting standards for data exchange and terminology, while ensuring – both individually and collectively – that privacy is protected and data remain secure (OECD, 2019[55]).

6.4.2. Common global health data standards are needed

Solving interoperability problems involves promoting the widespread adoption of public global standards and also filling important gaps in standards. A range of commendable initiatives are currently in play, some of which are outlined below.

A study by a team of scientists advising the United States government on weaknesses in health care interoperability in the United States recommended overcoming gaps by using a public Application Programming Interface (API) based on Fast Healthcare Interoperability Resources (FHIR) (AHRQ, 2014[56]). An API is a software that acts as an intermediary or translator enabling two different software applications to talk to each other (send and receive information). FHIR is a draft standard describing data formats and elements for exchanging electronic health records. The standard was created by the Health Level Seven International health-care standards organization (HL7). SMART on FHIR is an open, standards-based platform for medical apps that breaks down existing barriers for electronic health record systems to be able to benefit from existing medical apps (Smart, 2019[57]). FHIR standards may reference existing terminologies, classifications and coding standards, such as ICD or SNOMED.

Several global interoperability initiatives exist. LOINC, for example, is a standard for coding laboratory data maintained by members within the non-profit research community (LOINC, 2019[58]) and Health Level 7 International (HL7) which is a non-profit entity with a global membership developing standards for the exchange and sharing of electronic health information (HL7, 2019[59]).[2]

The private sector is also active in this space. The Argonaut Project, an initiative that ran from 2014 to 2018, involved a consortium of health technology companies and health care organisations in the United States, which developed FHIR implementation guidelines for use cases identified as high priorities for patients, providers and industry (HL7 FHIR, 2018[60]). The work included guidelines for data query for individual patients including a common clinical dataset, integrating apps into EHR records, provider

directories, scheduling health care appointments, access to text-based clinical notes, accessing clinical data for a roster of patients (dataset creation), and integration of simple questionnaires into EHRs. Another initiative is the Da Vinci project (Box 6.2).

Both the Argonaut and DaVinci projects address the interoperability challenges within the United States where these are particularly acute due to a fragmented landscape of health care provision and reimbursement. Nonetheless, the guidelines help to establish standards that may have broad international applicability and could support objectives of greater *global* interoperability of health care data.

In Europe, the GO FAIR Initiative, funded by the Ministries of Science in the Netherlands, Germany and France, promotes the practical international application of FAIR principles (FAIR, 2019[61]). FAIR guiding principles standardise the management and stewardship of digital data so that they may be re-used for future research. The four FAIR principles are **findability**, **accessibility**, **interoperability** and **reusability**. FAIR principles are increasingly required as part of publicly funding scientific grants (Wilkinson, 2016[62]) (Wilkinson et al., 2016[63]).

An implementation network of the GO FAIR Initiative is a consortium of academic centres and private sector companies who are developing secure data accessibility technology called *the Personal Health Train*. This is a technology enabling data custodians, such as health care providers, health authorities, researchers, governments, and individuals to enable access to and use of the data within their custody by third parties without having data ever leave the custodian. Data queries are submitted over secure data tracks, mobile workflows using virtual machines, connecting the stations (data custodians). Stations set the rules upon which data access is permitted or restricted. Personal Health Trains are developing in Netherlands, Germany and Switzerland (GOFAIR, 2019[64]).

The European Health Data and Evidence Network (EHDEN) is a private and public sector shared investment in developing an approach to standardising a wide range of health data in Europe (administrative, clinical, and patient-reported outcomes data). It aims to create a common data model to facilitate health statistics, monitoring and research undertaken by governments, universities and private sector entities, such as for pharmaceutical research (EHDEN, 2019[65]).

EHDEN is the new flagship project of the EU Innovative Medicines Initiative (IMI2) planned from 2018 to 2024. The IMI is a public-private partnership with funding from the public sector through an EU Horizon 20/20 research grant and the private sector through the European Federation of Pharmaceutical Industries and Associations (EFPIA). EHDEN is mapping a diversity of clinical, administrative and other health data including patient-reported outcome measures to a common data model permitting cross country medical research and research into outcomes-based health care. EHDEN is a federated network of data custodians and data sources across the EU and aims to map 100 million health records within its first mandate.

Work is also underway among the International Consortium for Health Outcomes Measurement (ICHOM), Intermountain Healthcare in the US and the Ministry of Health in the Netherlands, to facilitate the interoperability of patient-reported outcome measures and the implementation of standardised outcomes measurement in clinical workflows. The objective is to develop a ‘common language’ of health outcomes that will ensure that the semantic meaning of outcome data is preserved as data are interpreted across different technical platforms. This interoperability will facilitate global benchmarking of patient-reported outcomes.

However, an emerging – and unintended – risk is that the multitude of initiatives will actually exacerbate the challenge they are trying to solve. The work that has taken place to date needs to be consolidated, and countries should agree and gather consensus on standards for the growing range of data relevant to health that can and should be shared across borders to advance local and global health policy objectives. This effort needs to be coordinated globally and to involve a range of stakeholders in data development and use in both the public and private sectors. An international organisation such as the WHO or the OECD could facilitate this needed collaborative work.

Box 6.2. The DaVinci Project

The DaVinci project is a private sector initiative involving health IT professionals and health care industry leaders who are developing FHIR implementation guides (IG) for health care payers and providers to enable appropriate clinical data sharing and metrics for data sharing between payers and providers in support of value-based health care (HL7 International, 2019[66]). Payers, health systems, and other industry participants identify use cases involving clinical and administrative health data sharing. The objective is to minimize the development and deployment of hundreds of customised solutions between payers and providers by developing national standards, implementation guides and reference implementations to promote interoperability among all payers and providers. The project began in January 2018 and includes, for example, the following key components:

1. *Proof of 30-day medication reconciliation post hospital discharge.* An important quality of care metric increasingly required for value-based payment incentives in the United States. Developing implementation guides for this indicator involves sharing data at multiple levels: from the inpatient discharge records, discharge medications list, the exchange of the discharge medications list with the responsible provider, such as a primary care provider, and inclusion of the list within the responsible provider's electronic medical record (EMR), to reconciliation of all medications and an attestation of reconciliation.
2. *Exchange of clinical data (CDex).* Exchanges of clinical data from EHRs about patients' prior, current or planned health care services are necessary to more effectively manage patient care. These exchanges may be among providers, between providers and payers, or between providers, payers, and a third party, such as quality management organisations involved in value-based care. Implementation guides are being developed and tested to standardise the method and formal representation of these exchanges.
3. *Gaps in care and information*. Implementation guides are being developed for two types of gaps that affect patient outcomes and value-based health care: First, disparities between claims and clinical records that make it hard to tell if best care practices have been followed. Such as missing A1C test results for diabetes patients, or prescription of insulin to a patient missing a diagnosis of diabetes. Secondly, incomplete health care information, such as a referral for cancer treatment that is missing the date of diagnosis and stage at diagnosis will affect care coordination. The guide aims to enable bi-directional, real-time FHIR-based communication that reconciles payer information with clinical EHR data.
4. *Chronic Illness Documentation for Risk Adjustment*. Exploratory work toward potential guidelines is underway. Guidelines would enable payers and providers to use a standard protocol for exchanging information about chronic illnesses and a common terminology to describe chronic illnesses in order to exchange and use this information for risk adjustment and health care quality indicators.
5. *Patient Cost Transparency.* Exploratory work is underway for guidelines that support providers and patients access in real time, through the EHR system, to view the costs of prescription medicines, medical devices and medical services from payers so that this information could be taken into account during conversations related to medical care.
6. *Laboratory results.* Exploratory work is underway toward guidelines that would enable exchange of information about lab results. These guidelines are particularly challenging due to the high number of laboratories and wide array of laboratory tests in the US.

6.4.3. Data security in the digital era is greatly enhanced by global collaboration

Concerns about data breach and re-identification risks limit health data sharing within and across borders. Recommendations for reducing risk of data breaches and cyber-attacks included training staff about data security and phishing risks and implementing two-factor authentication for staff access to systems. It is also essential to have good cyber security around all the points of access to data, such as internet accessible servers and protocols for file transfers and remote data access.

New forms of encryption are being used that can protect data in transit between authorised parties and while they are within a cloud. In particular, a technique called Homomorphic Encryption can allow data held in a cloud to be analysed without first being decrypted. This technique has been tested to allow clinical sites to share aggregated data with multiple researchers at other sites without potential exposure to hacking by untrusted third parties (Raisaro et al., 2018[67]). The technique has also been tested and found able to be used in analysis predicting 30 day hospital readmissions from data within EHR systems (Chou et al., 2018[68]).

Emerging risks, such as quantum computing, also need to be addressed collaboratively. Research by governments in the United States and United Kingdom has sought to find a solution for quantum computers breaking public key cryptography (NSA, 2016[69]; Campbell, Groves and Shepherd, 2014[70]). It is possible to combine quantum devices with classical computers to enhance security and, in the longer term, to use quantum computers to offer greater security than classical computers can provide (Wallden and Kashefi, 2019[71]).

A technique called lattice cryptography, where data are encrypted inside mathematical lattices, has been developed by IBM and may be unbreakable, even with quantum computers while still being efficient when compared with public key cryptography. This technique is a form of fully homomorphic encryption and therefore it can be used to perform analysis on an encrypted file without first decrypting the data. As quantum computing will become increasingly used over the next decade, moving toward encryption solutions that work today and that will be future proof is worth exploring (Lyubashevsky, 2016[72]).

International cooperation is absolutely essential to harness the value of emerging technologies and techniques in order to foster a safe and productive data sharing environment. Implementing harmonised governance frameworks as set out in the OECD Council Recommendation calls on countries to maximise the potential and promote the development of technology as a means of enabling the availability, re-use and analysis of personal health data while, at the same time, protecting privacy and security and facilitating individuals' control of the uses of their own data ((OECD, 2019, p. Section III.8[55]). Security threats are increasingly global in scope, and global cooperation toward risk mitigation would be mutually beneficial.

6.5. Conclusion

Cross-country collaborations involving sharing health data contribute to research, innovation and to improving health and health care. Changing disease patterns, scientific advances and knowledge of the complexity of disease make the pooling of data and sharing of information across countries more important than ever. Digital technology has created the technical basis to do so. However, risks are also evolving. Countries need to work together to lay the essential groundwork for governance of multi-country projects involving health data and for investment in infrastructure for multi-country initiatives, including in the quality and standardisation of key health data and in data security.

International collaboration on specific topics and diseases has a rich and fruitful history. A growing number of governments and international organisations are investing in health information and research infrastructure for cross-country data exchange and collaborative work. This requires an enabling policy environment that addresses the challenges outlined in this Chapter, including threats to data security and impacts upon health systems of the commodification of patient health data. Collaboration is needed to develop harmonised approaches to health data governance, including protection of patient privacy and

data security, and to invest together in standards to improve health data content and interoperability for high priority research and statistical work in the public interest. Only such cooperation will create the environment that is necessary for discovery and innovation to address complex health problems that are global in scope.

The OECD Council Recommendation on Health Data Governance calls on countries to identify and remove barriers to effective cross-border cooperation in the processing of personal health data (OECD, 2019[55]). To support countries in this work, the OECD could serve as a coordinator for a global effort to address challenges that limit cross-border collaboration in research and monitoring with health data. In particular, OECD can support the development of global standards for data content and exchange, support global collaboration for the identification and response to data security threats, and foster a harmonised approach to health data governance to facilitate multi-country projects.

The OECD will also continue to support countries through on-going monitoring of progress toward research infrastructure that is truly global in its scope, that fosters research in the public, non-profit and private sectors and that yields benefits for patients and health systems.

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Notes

[1] These entities may be in another country or in a different Federal State of the German Republic to where the data were generated or the data subject resides.

[2] Global health data standards also require an accompanying definition of contents. For example, FHIR has several internal, restricted value sets to define content. But more frequently FHIR references terminologies, classifications or coding standards. These may be LOINC, SNOMED CT, ICD or others. There is in fact a growing trend towards referencing internationally accepted terminologies in different data standards, like FHIR, DICOM etc. To accommodate this development SNOMED International has released the Global Patient Set (GPS) for use under a free license. The GPS aims at meeting the main need for an information content standard in FHIR data standards.

7 Harnessing data to manage biomedical technologies

Luke Slawomirski

Routine and real-world data (RWD) – data that are generated during normal health system activities – can be deployed to advance evidence for medical technologies such as drugs, medical devices, combination products and precision medicine. Health systems have typically relied on evidence generated through prospective trials to inform the biomedical technology ecosystem, including discovery, research, policy and practice. While highly rigorous, clinical trials have a number of limitations. Scientific advances and changing global health needs, together with growing volume of electronic data and the technology to analyse them, mean that evidence from prospective trials can and should be complemented by real-world evidence (RWE) generated from routine data. Using examples and survey results, the chapter discusses the opportunities, challenges and policy implications of using RWD in regulating, pricing and using biomedical technology. It provides recommendations for policy makers and other stakeholders on how to implement a new data-driven approach to manage biomedical products more effectively.

7.1. Introduction

Data generated in health care are well suited to inform the development, regulation and use of biomedical technologies (Box 7.1). Almost all activity in a modern health system generates electronic data – clinical, demographic, administrative, and financial. These data contain valuable information, including how treatments, drugs, medical devices and medical products perform in routine clinical use. This information can help improve drug discovery, research and development, regulation, health technology assessment (HTA), pricing, and clinical practice. It can lead to better technologies and therapies, and more informed decisions on their use and management by patients, providers, regulators and payers.

Traditionally biomedical science has relied on prospective research methods – most classically the randomised controlled trial (RCT) – to generate evidence and knowledge on the safety, efficacy and other measures of performance of medical products. RCTs are, and will continue to be, the gold standard of producing evidence in medicine. But they are complex and costly. Meanwhile changing disease patterns, emerging health needs and recent advances in the biological sciences are creating new challenges that are difficult to manage with prospective research methods alone.

A need has emerged for evidence from prospective research to be supported by evidence extracted from routine data. This was not feasible when routine or real-world data (RWD – Box 7.1) were stored in paper records and ledgers, scattered across many health care facilities and organisations, which was a factor for the separation of research from practice – a separation that has become embedded in the health sector.

The world has changed. Digitalisation and the development of technologies to store, manage and make sense of vast amounts of electronic data mean that these can be put to work. The resulting knowledge can complement evidence from prospective research in answering a growing range of questions about the performance of medical products and health care interventions. This model of continuous, iterative learning and improvement of products and services has been the norm in a range of other industries for some time. It is yet to be embraced systematically in the health sector.

This chapter focuses on how a new approach that harnesses RWD to complement existing knowledge can be instituted to better manage medical technologies and products in health systems. The challenges to the traditional approach are discussed, along with the opportunities presented by the emergence of digital technology. Several examples are used to illustrate how routine and RWD have been used to generate valuable knowledge regarding the performance of medical products. However, health systems are not harnessing the full potential of RWD in this regard, with the key barriers centred on capacity, governance and infrastructure. The chapter finishes with a set of actions required by policy makers and other stakeholders to overcome these challenges and usher in an approach that is better suited to 21st century needs and opportunities.

Box 7.1. Terminology used in this chapter

Biomedical technology (medical products)

A 2017 OECD report on managing new technologies in health care defined health technology as "the application of knowledge to solve practical clinical and health problems, including products, procedures and practice styles that alter the way health care is delivered" (OECD, 2017[1]). The technology discussed in this chapter – biomedical technology – is a subset of health technology that primarily comprises:

- pharmaceutical products (drugs and medicines)
- medical devices – instruments, appliances, implants or reagents for in vitro use, software, material or other similar or related article, intended for the specific medical purpose(s) of diagnosis, prevention, monitoring, treatment or alleviation of disease or injury; investigation, replacement, modification, or support of the anatomy or of a physiological process; supporting or sustaining life; control of conception, and does not achieve its primary intended action by pharmacological, immunological or metabolic means (WHO, n.d.[2]).
- products that combine two or more of the above (drug eluting cardiac stents, or therapies based on identification of genetic and other biomarkers – commonly referred to a precision medicine).[1]
- Technology can also encompass scientific discovery and improvements in the quality of care delivery more broadly. While routine data can certainly be used to advance these elements, they do not feature prominently in this chapter.

Routine health data

Routine, or routinely collected, data are data generated by clinical or administrative activities that occur in a health system. Routine data may include administrative and/or clinical data generated by health care facilities, cost data, insurance claims, medication dispensing data, and mortality.

Medical records are also a type of routine data, containing information of patient contact with a health care system including diagnoses, therapies, laboratory and imaging results, outcomes and contextual information on demographics. Electronic medical records are being increasingly implemented. These can be maintained at local level in individual medical practices or hospitals or as part of a universal electronic health record (EHR) capturing all interactions with the health care system. The repurposing of electronic medical record data across a population is much simpler if these are consolidated or can be linked.

Data collected in disease or clinical registries are considered routine if the registry is perennial (as opposed to established for a specific, time-limited study). Registry data can also be a rich source of information on specific treatments or diseases.

Routine data can contain health, financial and other information. For example:

- clinical information such as morbidity and mortality, contact with health services, or hospital admissions;
- patient-reported outcomes measured using a number of available condition-specific or generic instruments;

  economic or financial outcomes of the using of medical and non-medical resources and their associated costs.

Real-world data; real-world evidence

The terms real-world data (RWD) and real-world evidence (RWE) are coming into regular use and feature in this chapter. RWD simply describes data relevant to health and health care generated outside the research setting of. clinical studies and trials. RWD can draw on a wide range of data sources, including: routine data; genomic and other "omics" data; health surveys; observational studies; data from wearable devices; and social media.

Real-world evidence (RWE) is the insight or knowledge derived from the analysis of RWD, based on a specific research question or questions. Generating RWE requires a research plan, analysis and interpretation of RWD, which is but one of several inputs. The United States' Food and Drug Administration (FDA) simply defines RWE as 'evidence from clinical experience'.

1. Precision medicine is defined as refining the understanding of disease prediction and risk, onset and progression in patients, to inform better selection and development of evidence-based and targeted therapies and associated diagnostics. This is achieved by taking into account the patient's genomic and other biological characteristics, as well as health status, medications patients are already prescribed and environmental and lifestyle factors (OECD, 2017[1]).

7.2. Scientific progress, changing disease burden and financial pressures are challenging the conventional approach to evidence generation

Under the existing model, evidence and knowledge regarding the benefits, risks, harms and costs of biomedical technology are generated in dedicated research settings. Prospective research methods, such as the RCT, are the conventional means to assess the clinical effects of products and therapies.[1] The results of clinical trials inform and influence *inter alia* regulatory (market entry) authorisation, health technology assessment (HTA), and reimbursement decisions. Results also influence how the product is used in the clinical setting including how information for patients its benefits and risks is framed. Researchers and industry also use this evidence to refine existing products and discover new ones with good therapeutic potential.

After a product has entered routine clinical use, the information captured in medical records and other sources has traditionally not been used to re-evaluate its performance outside the prospective research setting. The separation between biomedical research and medical practice is a defining characteristic of medicine (and, as discussed later, a vestige of the pre-digital era). It can impact many aspects of health care and medical practice, affecting patient outcomes and the way in which resources are allocated (O'Mahony, 2019[2]).

In terms of the biomedical technology ecosystem, the existing paradigm of knowledge-creation is being challenged on several fronts: cost considerations, establishing effectiveness, changing health needs and rising expectations, and the statistical power to detect rare effects and advance the promise of precision medicine.

7.2.1. Clinical trials are the gold standard, but come at a high cost

RCTs are highly useful to generate robust evidence about new (hitherto unused) products. But they have some important limitations. They can be very complex and therefore costly to undertake. Prospective studies require a dedicated infrastructure including a sponsor, investigators and other staff. The planning and preparatory phase alone can take years. Institutional review can add another layer of complexity (and cost) in some jurisdictions (Silberman and Kahn, 2011[3]).

The considerable resource requirements limit the number of trials that can be conducted, restricting the number of research questions that can be explored for a particular product or disease. This is a considerable limitation when potential questions and possibilities are proliferating *inter alia* through the explosion of genomic data, advances in biological understanding of diseases and the growing number of competing products on the market. For instance, over 60 new therapeutic indications in haematology-oncology were approved in 2018 alone in the United States (FDA, 2019[4]).

This has concrete consequences for patients, clinicians, regulators and payers. For example:

- 'Combination therapy' is emerging as one of the more promising treatment modalities in oncology. The many drugs and therapies that can potentially be combined in various sequences and doses (as well as basing them on patient-related biomarkers) create a large number of possible therapeutic permutations. The emergence of sequencing-based genomic assays and the (potentially) hundreds of mutations in many cancer subtypes raises the combinatorial complexity to unprecedented levels (Allegretti et al., 2018[5]). It would be impossible to investigate even a small percentage of these relying on prospective research alone.
- When a new product enters a crowded market, it is not feasible to conduct head-to-head RCTs on comparative performance with all alternative treatments. This was recently illustrated following European approval of a new antidiabetic drug (canagliflozin) which has 18 relevant comparators (against few of which the new drug had been investigated in RCTs (EUnetHTA, 2014[6]). The lack of evidence of comparative performance between on-market products leaves clinicians, HTA agencies and payer organisations with significant uncertainty in their decisions.
- In some medical conditions, the benefits and risks of a treatment can be predicted by individual patients' demographic and physiological characteristics (the underlying principle of precision medicine, discussed in more detail below). But it is costly to generate the evidence necessary for developing these prospectively. The Vienna Prediction Model (VPM) used to guide clinicians in the initiation and duration of anticoagulant therapy (to manage the risk of bleeding) was developed on the back of a prospective study that took approximately 17 years, at a cost of over EUR 12 million (Eichinger et al., 2010[7]). Establishing similar algorithms in this fashion for the growing constellation of therapies and treatments is not feasible.

7.2.2. Effectiveness and rare events are difficult to establish prospectively

Clinical trials are typically based on planned and pre-authorised protocols. Suitable participants (subjects) are carefully selected and enrolled. This places natural limits on the number and the diversity of participants. In many cases, patients that do not fit specific criteria based on co-morbidities or age, for example. These individuals are screened out to increase the likelihood of isolating the effect of the intervention under investigation. This means that the enrolled patient sample may not be representative of the patients who will eventually use or receive the product. In an extreme example, a study to test dangers of mixing alcohol with a drug to treat sexual dysfunction in women was conducted using a sample of 23 men and two women (Yale School of Medicine, 2015[8])

Given the nature of medical devices (e.g. the difficulty of using placebo controls and double blinding in clinical trials as well as the incremental innovation cycles in which they are developed), the evidentiary requirements may be less rigorous than for pharmaceutical products, for which placebo-controlled trials are generally required. Nevertheless, device trials follow a similar process, with prospective design and careful patient selection (OECD, 2017[1]).

As such, clinical trials generally only provide evidence of product *efficacy* – the product's performance under ideal and controlled circumstances created by judicious selection of participants, careful administration of treatment and attentive follow-up (Singal, Higgins and Waljee, 2014[9]; Eichler et al., 2011[10]). This is distinct from the *effectiveness* of a product-- how it performs under normal clinical

conditions, accounting for external patient, provider and systemic factors that may modify the intervention's effect, but that can reasonably be expected in routine clinical use. While evidence of efficacy is needed for regulatory approval, decision-making in health care and health policy also requires evidence of effectiveness.

Moreover, prospective trials are rarely large enough to detect rare treatment effects and outcomes. Studies with a small number of participants are common. Even in a controlled trial of 2 000 patients, which is not a particularly small number of participants, 1 000 patients would be exposed to the intervention with the other 1 000 forming the control group. Say the intervention has an unknown effect that occurs in one administration per 1 000. The probability of *not* observing this effect at least once in a trial of that size is a substantial 37%.[2] Even if it were observed, an accurate statistical estimate of the underlying effect of the intervention would be impossible to make with such a small number of observations. Moreover, if there is a natural background effect occurring irrespective of patients' receiving the intervention, detecting an increase becomes even more challenging.

Of course, infrequent outcomes can be adverse or beneficial. Their detection can facilitate avoiding unnecessary harm or elucidate additional benefits for patients. For example, it took two years and 61 deaths to withdraw benoxaprofen (Opren) from the market, a drug launched in 1980 following clinical trials involving over 3 000 participants. Either way, studies of much greater size are required to accurately gauge risks and identify any associated predictive variables prospectively (Eichler et al., 2018[11]).

In addition, gene or cell therapies will increasingly form the basis of future medical interventions. These products bring unique challenges for evidence generation. Some may only require once-in-a-lifetime administration. Intended and unintended effects, their onset and duration, will in some cases only be evident after long periods, perhaps decades. These factors will challenge the traditional paradigm for reasons similar to those outlined above.

7.2.3. Changing health needs and disease profiles create further challenges

Chronic conditions are becoming the most pressing public health issue in all regions of the world. Generating evidence on the prevention, management and even cure of debilitating, but not necessarily fatal, long-term conditions is challenge.

For example, Alzheimer's disease – a debilitating form of dementia – is an emerging global health and welfare problem and a matter of major policy concern. In the absence of a cure, initiating treatment after symptoms develop may be too late to prevent or reverse decline and alter the patient outcome. Potential preventive and curative therapies – whether pharmacological, mechanical, neuro-electronic or comprising a combination of modalities – may be most successful when initiated in people with (suspected) indicative biomarkers years or even decades before the appearance of any clinical signs or symptoms (Eichler et al., 2018[11]). Other chronic and degenerative diseases including cancer, diabetes, and cardiovascular and arthritic diseases present similar research challenges.

Appraising the performance of such treatments (which may be administered in various combinations – similar to the oncological therapies discussed above) would be very challenging and costly in a dedicated research setting. Patient follow-up would need to span a very long time (potentially an entire lifetime), and require a massive sample, not only to account for attrition of study participants, but also to create sufficient statistical power that can elucidate the predictive validity of the pre-morbid characteristics and biomarkers.

7.2.4. Fulfilling the promise of precision medicine will be difficult under the existing model

The emergence of precision medicine presents another challenge that radically reorients interest in clinical studies from coherence to inter-individual variation.

In the highly structured context of a clinical trial, variance is considered noise that needs to be screened out in order to maximise internal validity and the chance of demonstrating a treatment effect. But the biological and genetic basis for the variance is now understood to be potentially predictive of the patient's response to therapy. Understanding the associations will facilitate getting the right interventions to the right patients (and avoid it being given to the wrong patients) – thus helping to advance the promise of precision medicine. This transforms inter-individual variance from an inconvenience to be minimised to the key focus of the research.

Conventional trials are underpowered for the complexity presented by numerous biomarkers that reflect this variance, and the requirement for participants to be homogeneous is irreconcilable with the genetic, molecular and therapeutic diversity central to the precision medicine approach.

This is arguably *the* area where the intelligent use of routine and RWD can add the most value. A recent systematic review of the opportunities and challenges of routine data analysis in health and biomedical science identified precision medicine as that the most frequently discussed opportunity for advancement (Galetsi, Katsaliaki and Kumar, 2019[12]).

7.2.5. Raised expectations are a further challenge to the current approach

Precision medicine currently embodies the decades-long advancement of biomedical science. This advancement has – for better or worse – raised the expectations of patients, their families and carers and the public. This presents another challenge to the traditional paradigm, perhaps ironically given the central role played by prospective research methods in this progress.

Patient groups increasingly expect rapid access to drugs that have the potential to improve or cure their conditions and a growing number of promising treatments are being fast tracked for marketing approval. This necessitates the close monitoring of, and continued reassessment of risks and benefits post-approval – using clinical practice to also generate evidence at the same time.

Furthermore, these technologies often come with high price tags, so assessing their outcomes in routine practice becomes necessary to confirm their cost-effectiveness. Collectively, these issues illustrate the need for a new approach to generate evidence and knowledge in health care.

7.3. Digitalisation makes a new paradigm possible

The existing approach to creating knowledge in biomedical science is characterised by a separation of evidence generation from everyday health care activity – or research from practice. In many ways, this is a legacy of the pre-digital age, when all clinical and administrative activity had to be recorded in hard copy. The resulting data were buried in paper ledgers and medical records, scattered across disparate health care provider organisations and administrative agencies. Systemic aggregation and analysis of these data were technically and logistically impractical. It is hardly surprising that little thought was given to the knowledge and learning that they could potentially generate. Reliance on the research setting, and its separation from routine activity became institutionalised. Ignoring the potential of re-purposing existing data was habituated.

7.3.1. Routine and real-world data open new possibilities for generating evidence and knowledge

As has been mentioned out a number of times already in this report, the digital era has revolutionised the nature of data, information and communication. In health care, digitalisation commenced not long after the appearance of personal computers in the mass market. Administrators implemented these information technologies in their organisations, and most non-clinical routine health care data became electronic.

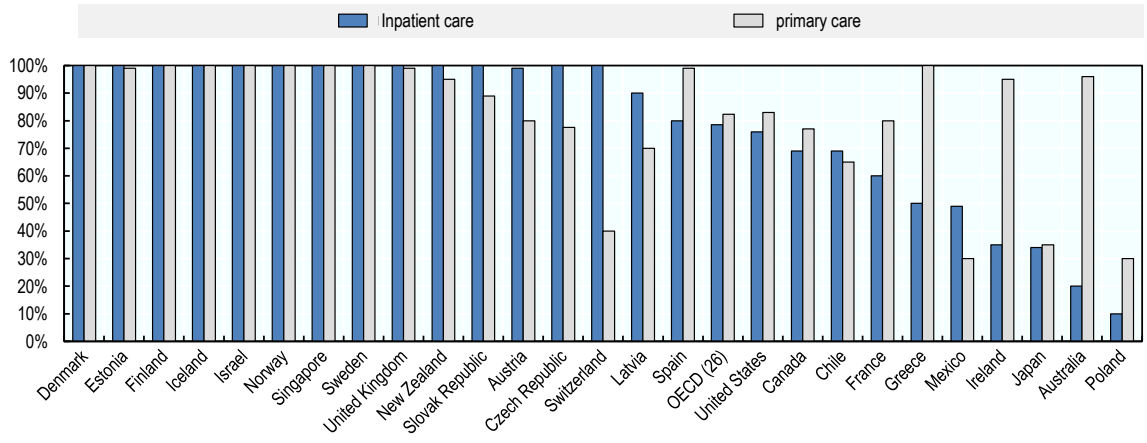
Digitalisation of clinical data (patient records) has progressed more slowly but is accelerating (Oderkirk, 2017[13]). In many OECD countries, electronic medical records have been implemented across health care sectors, including 100% of primary and inpatient care.

The diffusion of electronic medical and health records in OECD countries was, in 2016, estimated to be 81% for primary care physician practices, and 76% for inpatient care (Figure 7.1). Implementation is reported to have increased considerably since 2012 (OECD, 2013[14]). Within a few years, the vast majority of patient encounters with any part of the health care system in developed countries will be recorded digitally, and the resulting data stored electronically.

Clinical data can be very granular, especially if free text is included, and can be a source of rich information about various aspects of the care process, including the performance of medical technologies. Linking clinical data with administrative information such as costs and expenditure enables insights into the real-world economic performance of care and its constituent parts. This knowledge can not only improve decision making regarding approval, HTA and pricing but also be deployed to spur future innovation, including the repurposing of existing technology as well as development of new treatments.

Figure 7.1. The majority of clinical records is in electronic form

Percentage of primary care physician offices and acute care hospitals using electronic medical records, 2016



Note: United Kingdom: England, Scotland and Northern Ireland (excludes Wales)
Source: OECD Survey of Electronic Health Record System Development and Use, 2016; Oderkirk (2017[13]), "Readiness of electronic health record systems to contribute to national health information and research", https://dx.doi.org/10.1787/9e296bf3-en.

Electronic data are non-rivalrous. They can be shared, used and analysed *ad infinitum*, which means that they can be a source of ongoing knowledge generation and learning. The potential for useful insights and learning is magnified when they are linked, especially at the patient- level. And the potential knowledge grows even further when other forms of real-world data can be linked – ranging from administrative and registry data to environmental and social data.

7.3.2. Other industries put their data to work to drive improvement and learning

A learning system is characterised by the way it links routine practice to the accumulation of knowledge in order to spur continuous improvement and innovation. A range of industries and endeavours have brought together doing with learning to deliver better services and products, generating commercial benefits as well as considerable consumer surpluses.

Airlines and aircraft manufacturers gather real-time flight data and integrate these data with historical information to improve operational safety, efficiency and performance. A routine commercial flight will transmit over 146 000 data points that will be analysed by the airlines, and manufacturers of the aeroplane and engines for continuous improvement and identification of risks. This has contributed to advances in engineering and performance (OECD, 2017[15]). Air travel is one of the safest modes of transport available and has never been cheaper or more accessible to the public.[3]

Modern agricultural machinery is equipped with sensors and transducers (like modern medical equipment) that collect and transmit by the internet a range of data on a range of variables: performance, environmental conditions, crop quality. Various actors (manufacturers, agricultural scientists) use these data in combination with information on weather patterns, soil composition, geolocation and historical crop yields to continually raise agricultural productivity, develop better products and equipment. (OECD, 2017[15]) This 'precision agriculture' approach enabled by continuous analysis and use of data can is reducing waste and improving global crop yields, with projected increases of up to 30% (National Institutes of Health, 2019[16]; OECD, 2017[15]).

The paradigm of using everyday data to improve quality and performance of products and services is perhaps most visibly deployed by online platforms trading in tangible and intangible goods. Firms such as Google, Amazon, Apple, Microsoft and Uber all harness data from daily customer interactions to continually improve their services.[4] This data-driven innovation has generated immense consumer welfare over the past two decades (Brynjolfsson, Hu and Smith, 2003[17]; Brynjolfsson, Eggers and Gannamaneni, 2018[18]).

7.3.3. Learning from real-world and routine data is demonstrably possible in the health sector

Learning is not yet an explicit goal of RWD, and many institutional barriers exist to creating an ecosystem conducive to continuous learning, even in the context of biomedical technologies. Nevertheless, some forward-thinking agencies and systems are deploying RWD for this purpose.

Regulators are already using routine data to monitor safety

Routine data are already deployed to inform providers and policy makers, predominantly on the safety of biomedical products (OECD, 2019[19]). For example, the European Medicines Agency used registry and administrative data to quantify the risk of metformin use in patients with renal impairment, showing a much lower risk than previously estimated. This led to a modification of contraindications on the product label without the need for an expensive prospective post-marketing study (Li et al., 2016[20]).

Four large administrative claims databases in the United States were used to compare several diabetic drugs for risk of subsequent cardiovascular events and amputations.[5] Over 700 000 de-identified patient records were used in the study, which generated knowledge relevant to patients, providers, regulators and payers. For example:

- One class of drug (SGLT2i) was associated with a significantly lower risk of heart failure than the other class investigated – both overall and in a sub-population with pre-existing cardiovascular conditions;
- No difference in heart failure risk was observed between a specific drug (canagliflozin) and others in the same class;
- No difference in amputation risk was observed between the drug classes – both overall or in the sub-population with pre-existing cardiovascular disease.

The results for heart failure were consistent with those of (much smaller) clinical trials. However, the amputation risk results deviated from previous findings. For example, canagliflozin was associated with increased risk of amputation in a previous study of 10 000 patients (Neal et al., 2017[21]; Ryan et al., 2018[22]).

Shah et al. (2015) focused on the clinical safety of proton pump inhibitors (PPIs) – one of the most commonly prescribed classes of drug in the world – examining their association with adverse cardiovascular effects. These effects were previously recognised among PPI users with pre-existing cardiovascular problems. The study sought to examine the existence of the association in the general population, thus requiring a sample large enough to be representative of the population. The authors analysed two large datasets containing 2.9 million individual patient records spanning 1994-2011. The results suggested a previously unknown association between PPI use and an elevated risk of heart attack in the general population, including among younger patients (Shah et al., 2015[23]).

The pre-eminent example of harnessing routine and RWD to create evidence for policy and practice is the United States Food and Drug Administration's (FDA) Sentinel initiative (Box 7.2) – a nation-wide electronic pharmacovigilance programme that accesses personal health data of over 200 million patients. What distinguishes Sentinel from other regulatory uses of RWD is its systematic nature – it operates continuously in the background of all health system activity rather than relying on isolated, ad-hoc investigations or voluntary reporting. Sentinel has been institutionalised and the fact that ten years after its inception it still rates as one of the best examples of regulatory RWD use is perhaps an indictment of how slow health systems have been to embrace this approach offered by digital technology and electronic data.

Box 7.2. The Sentinel initiative

The Sentinel initiative of the United States FDA accesses personal health data of over 223 million United States residents to monitor adverse effects in approved pharmaceuticals and medical devices in routine clinical use. The data are scattered across a large number of health care organisations, payers, providers and agencies. The key feature of this programme is its distributed nature. Custodians (referred to as "partners") maintain full control over their data, which remain behind existing firewalls. At no stage does the Sentinel programme take possession of any data.

The distributed system is based on common standards to ensure that all data are formatted to agreed specifications. This enables Sentinel to send electronic queries about the safety of technologies in current use to which the partner returns only the results. Notably, administrative (claims) data form the backbone of the Sentinel system due to their reliability in providing complete longitudinal information on the application and outcomes of biomedical interventions. However, the infrastructure also enables links with EHR and registry data.

The Sentinel initiative has generated important knowledge not discernible from clinical trials, to enable several important regulatory decisions. Examples include identification of intussusception risks associated with rotavirus vaccines, as well as evidence suggesting no association between human papillomavirus vaccination and blood clotting (FDA, 2015[24]). The programme has thus eliminated the need for expensive post-marketing studies in a number of products, saving millions of dollars (Ball et al., 2016[25]). More recently it has been deployed to conduct pragmatic (retrospective) clinical trials using the data at its disposal. For example, an 80 000-person randomised study tested the effect of educational mailing to people with atrial fibrillation who were not receiving anti-coagulants (Platt et al., 2018[26]).

In addition to the distributed infrastructure, other key reasons for the success include trust and transparency. Data partners are actively involved in every step of the engineering and analytical processes. They have the ability of opt out of specific investigations. All evaluation protocols, including coding and specifications, as well as completed analyses, are published on the Sentinel website (http://www.fda.gov/safety/fdas-sentinel-initiative). The initiative was launched in 2008, initially as a pilot scheme called 'mini Sentinel' extended to its current scope and scale in 2016.

Evaluating effectiveness and comparative performance of medical products are also possible

Monitoring the safety of products is fundamental to regulating medical technologies across a health system. However, real-world and routine data can also be deployed to inform several other decisions in the medical technology ecosystem including marketing authorisation, HTA, pricing and appropriate clinical use. The volume of research and number of published studies that use real-world data to assess the effectiveness and cost-effectiveness of medical products is on the rise, creating promise as well as caution (Kim and Kim, 2019[27]; Farmer et al., 2017[28]). Nevertheless, real-world data studies have been used to establish evidence for cost-effectiveness and comparative effectiveness.

For example, coronary stenting is one of the interventions used to re-establish blood flow in coronary vessels. Stents used are either simple bare-metal stents (BMS) or drug-eluting stents (DES), which also slowly introduce an anti-coagulant into the blood flow. While DES have been shown to perform better, they are also more expensive. A recent study in Chinese Taipei assessed the comparative cost-effectiveness of the two products using seven years of health insurance claims data (Cheng et al., 2019[29]). While the study has some limitations, the findings suggest that DES are cost-effective over a five-year timeframe compared to BMS, partly due to a reduction in the number of subsequent medical interventions in DES recipients. Such information will be of interest to HTA agencies and payers, as well as providers and patients.

In another study focusing on PPIs, data from the Irish Health Services Executive Primary Care Reimbursement Services (HSE-PCRS) pharmacy claims database[6] were used to investigate potential cost reductions in PPI use. Several scenarios were modelled that would reduce expenditure without compromising effectiveness including switching to the cheapest medicine at initiation and after three months and substitution with another drug class (H2 antagonist). In 2007 over EUR 88 million was expended on PPI therapy for 469 708 claimants. The projected cost reductions under the five scenarios were considerable, ranging from 34% to 46% or EUR 30–EUR 40 million per annum (Cahir et al., 2012[30]). As 113 million PPIs are prescribed globally each year, the results of this and Shah et al (2015[23]) are of interest beyond Ireland.

Taipale et al (2017[31]) assessed pneumonia risk associated with use of benzodiazepine and Z-drugs (sedatives) among community-dwelling adults with Alzheimer's disease. The authors accessed the Medication Use and Alzheimer Disease (MEDALZ) cohort study that combined four datasets: prescriptions, claim reimbursements, hospital discharges and causes of death. Almost 50 000 eligible older adults diagnosed with Alzheimer disease were identified in the data. From this sample, 8 501 taking sedatives were matched 1:1 with those not taking the drugs. The results showed an association with increased risk of pneumonia among patients taking benzodiazepines, but not among those taking Z-drugs. The risk of pneumonia was greatest within the first 30 days of use. (Taipale et al., 2017[31]). This knowledge can be used for developing and updating clinical practice guidelines, and for informing patients (and their carers) of risks associated with using these medications.

Evidence from studies using routine data can identify ways to reduce health care expenditure without compromising patient outcomes. A recent retrospective study of over 14 000 older adults with type 2 diabetes assessed the effect of switching from analogue insulin to human insulin. No clinically significant difference was observed (Luo et al., 2019[32]). However, the financial impact of policy based on this evidence could be profound. The majority of adult diabetics in the United States are treated with analogue insulin, which accounts for significant growth in expenditure on diabetes medications. A vial of human insulin can be purchased for USD 25 compared to a retail price of up to USD 320 for the analogue equivalent (Lipska, 2019[33]).

Nyström et al (2017) compared insulin therapy with oral glucose-lowering drugs (specifically SGLT2 and dipeptidyl peptidase-4 (DPP4) inhibitors) for their association with mortality, cardiovascular events and

severe hypoglycemia. The investigators linked patient-level data from three national datasets to create a sample of 37 603 patients. Of these, 21 758 were matched 1:1 with patients on traditional insulin therapy (bringing the total sample size to over 59 000). The data were of sufficient size and quality to enable comparison of the two novel drugs with insulin, showing that the SGLT2 inhibitor (dapagliflozin) was associated with a lower risk of mortality and cardiovascular events while the DPP-4 inhibitor was only associated with lower risk of mortality compared to insulin treatment (Nyström et al., 2017[34]).

7.3.4. Statistical methods and techniques as well as veracity of routine data require continued development and refinement

Despite the much larger samples enabled by retrospective studies using routine data, it is clear that such research designs have inherent limitations and can be prone to risks of bias (Kim and Kim, 2019[27]). However, methodologists are devising new approaches, techniques and methods – propensity score matching being one example – to attempt to overcome these limitations (Goodman, Schneeweiss and Baiocchi, 2017[35]).

Researchers in Sweden identified 24 retrospective studies using routine (registry) data in that country alone. The majority of these studies concerned cardiovascular and psychiatric drugs and linked prescribing data with two to three other sources. However, only two of the studies contributed to new knowledge, and the majority (15) had a high risk of bias based on a checklist from the Swedish Council on HTA focusing on subject selection, treatment, assessment, exclusion, reporting and conflicts of interest. The most frequently occurring problems were biases with selection, treatment and assessment. Authors concluded that observational retrospective studies based on routinely collected data such as registries could contribute to the evidence, but must deploy techniques to counter the inherent methodological limitations and risks of confounding in retrospective studies. Pharmaco-epidemiological expertise should form a part of the design and execution of such studies (Wallerstedt and Hoffmann, 2017[36]).

Nevertheless, the field is advancing, producing some noteworthy results. Fralick and colleagues (2018) replicated the results of an RCT to compare the effectiveness and safety of two drugs used to treat hypertension. The retrospective study used insurance and claims data of 640 951 patients. Results were almost identical to those of the RCT. However, while the original trial took approximately seven years at a cost of tens of millions of dollars, the study using real-world data took 12 weeks at less than a hundredth of the cost (Fralick et al., 2018[37]).

Similarly, the Vienna Prediction Model (VPM) for anti-coagulant therapy (outlined previously) was developed based on evidence generated by using prospective studies that took 17 years to conduct at a cost of EUR 12 million. The VPM was validated retrospectively using the clinical records data of just over 900 patients, pooled from several studies of venous thromboembolism risk prediction. This took six months at a cost of under EUR 100 000 (Marcucci et al., 2015[38]).

This is not the say that the original prospective research was unnecessary or that the new approaches using routine or RWD render clinical trials obsolete. Rather, the new techniques have reached a standard where the evidence they generate can be used by policy makers, practitioners and patients – at comparatively little cost. In addition, the techniques will continue to improve with further effort and use of data for retrospective studies.

Data quality, completeness and reliability also play an important part. Deficiencies in data veracity seriously undermine the robustness of any secondary research that is conducted using routine and real-world data. As described in other chapters of this report, data quality and completeness vary considerably across OECD member countries. Moreover, the standards and semantics used to encode information are not consistent, leading to problems with interoperability and linkage of data sets within and across countries.[7]

Data reliability and provenance may also be an issue in some circumstances. Here specific technologies and innovations can assist. Blockchain technology, for example, is used to ensure the provenance of

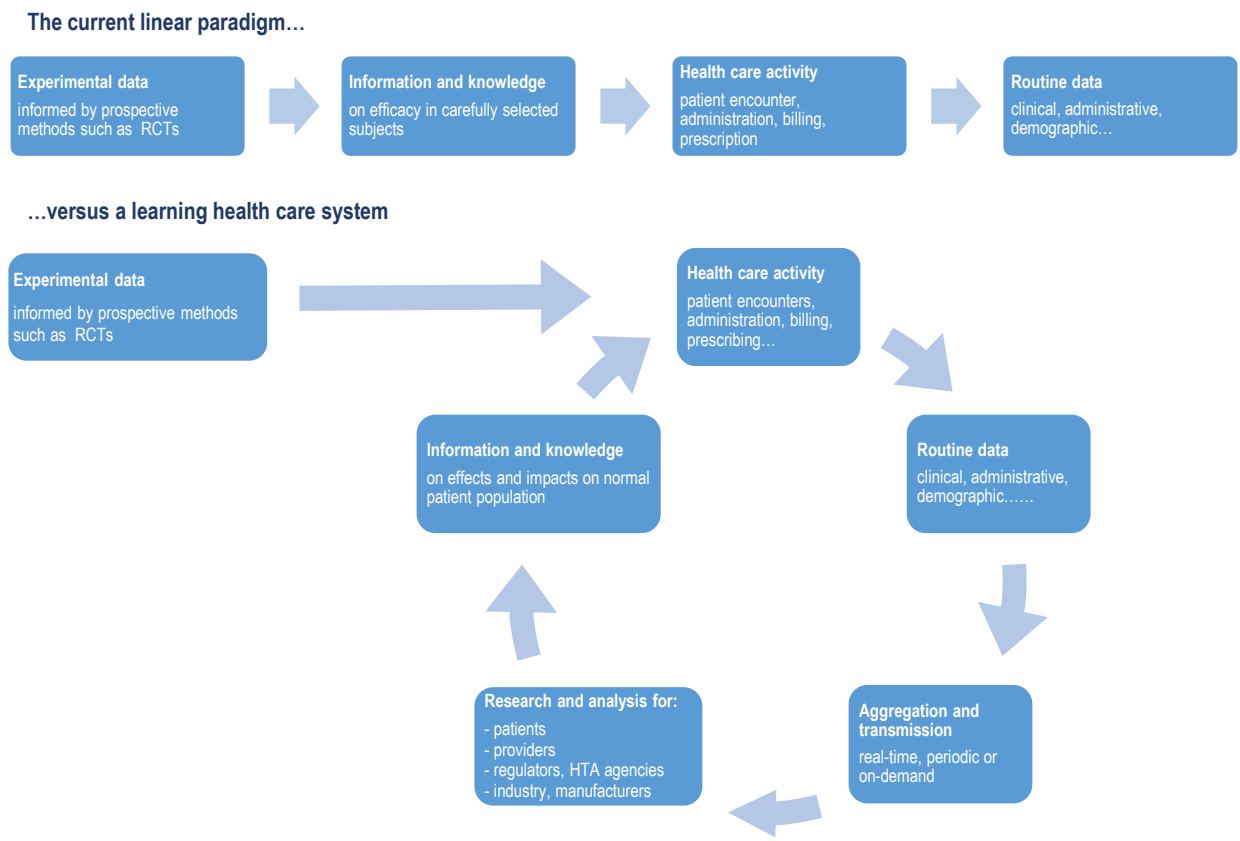
medical products and could be deployed to validate the accuracy of health data. Overall, however, addressing this issue requires governments to implement harmonised and fit-for-purpose health data governance frameworks – a key prerequisite of putting data to work that is discussed below and in other chapters of this report.

7.3.5. Real-world evidence to complement, not replace, traditional knowledge generation

The relinquishing of clinical trials in favour of studies using RWD is certainly not suggested. RCTs will continue to be the gold standard of generating information on the efficacy of new therapies and interventions. However, knowledge generated retrospectively is now well placed to complement evidence generated in the research setting given the (a) ubiquity of RWD in the digitalised environment, and (b) available methods and techniques available to create evidence from them at a fraction of the cost of prospective research. No valid reason exists to not provide researchers with opportunities to use routine data for this purpose and, at the same time, continue to advance the reliability and robustness of research design and methods.

The contrast between the current and the new approach of evidence creation is illustrated in Figure 7.2. In the 'learning health care system' paradigm, experimental data from prospective trials are still needed to generate evidence on new technologies, but this then feeds into a cycle that harnesses routine data for continuous, iterative learning and knowledge generation.

Figure 7.2. The current linear approach versus the cycles of improvement where RWD complements experimental data



Source: Adapted from OECD (2017[1]), *New Health Technologies: Managing Access, Value and Sustainability*, https://dx.doi.org/10.1787/9789264266438-en.

7.4. Patients and the public want and expect their data to be put to work

Despite their ubiquity, their non-rivalrous nature and the existence of methods to exploit them, using routine data to generate evidence about the performance of medical technologies still tends to be isolated and ad-hoc. However, to deploy them more systematically by academia as well as relevant agencies and authorities for public benefit requires some reflection on the attitudes and dispositions of the data subjects themselves – patients and the public, the latter both as potential patients as well as the basis for societal values and preferences.

7.4.1. Patients support secondary use of their data for scientific advancement

Those with most to gain from the new approach to managing medical technology – patients – are mostly in favour of their health data being used to generate new knowledge and facilitate access to better treatments. The European Patients' Forum (EPF), and EU-wide coalition of patient representative groups, have actively lobbied EU institutions to lower impediments to the use of personal health data for secondary purposes during debates on the EU data protection regulation (which came in to force in 2018 as the GDPR). In what was referred to as the 'datasaveslives' campaign, patient groups argued that privacy protection could be reconciled with use of personal health data for health care, public health and research purposes. While informed consent to such uses of data is an obligation and should be the default arrangement, EPF argued for exemptions in cases where it was not feasible to obtain consent or re-consent from data subjects (EPF, 2019[39]).

In the United States, patient advocacy groups support the Institute of Medicine's recommendations to enhance the productivity of health research with RWD, while maintaining or strengthening the privacy protections of personally identifiable health information (National Academies, 2009[40]). For example, the Friends of Cancer Research organisation actively supports the use of routine data in drug discovery, development and regulation (Friends of Cancer Research, 2016[41]).

Protecting privacy is a central component of efforts to harness routine data for research and other purposes. Arguably, the most vulnerable group in this regard are people with rare diseases, who – by definition – are at greater risk of identification during studies especially if these involve data linkage. Nevertheless, evidence suggests that patients suffering from rare diseases – while concerned about data security and misuse – support their data (e.g. biosamples and genetic information) being shared internationally for research purposes (McCormack et al., 2016[42]).

7.4.2. The public is also in favour if the necessary protections are in place

That patients are positively disposed to their personal data being deployed to improve care and outcomes is perhaps no great surprise. While privacy concerns are important for patients, they do not necessarily trump the use of data for purposes that can benefit others.

What about citizens and the public more broadly, who may not be as personally invested in the availability of, and access to, better medical interventions for specific diseases? Evidence suggests that the public generally expresses a similar disposition to patients, provided that they are confident that data remain secure and are used for the common good rather than commercial purposes. In a 2017 public consultation of EU residents, 83% of respondents either agreed (30%) or strongly agreed (53%) with the statement "Sharing of health data could be beneficial to improve treatment, diagnosis and prevention of diseases across the EU". Moreover, 73% of respondents said that they would be willing to share their health and personal wellbeing data with others through a secure infrastructure. The majority of respondents identified improved possibilities for medical research as a reason for supporting cross border transfer of medical data, a higher proportion than for the purpose of their own treatment (European Commission, 2018[43])

However, people are not supportive of *all* types of secondary use of their data. Other surveys suggest that support is generally conditional on the belief that data will be used to further the common good and people are less in favour of re-use of data by commercial organisations (Skovgaard, Wadmann and Hoeyer, 2019[44]). The backlash to the sharing of 1.6 million NHS patients personal data with DeepMind, a subsidiary of Google's parent company Alphabet, is an example of this prevailing sentiment (Loughran, 2016[45]). Meanwhile, Google and the University of Chicago Medical Center are facing a class-action because patient records shared in order to with the technology giant without stripping information, which, if combined with other personal data already in Google's possession (such as geolocation, social media and web browsing), could potentially identify individuals (New York Times, 2019[46]). The latter not only illustrates attitudes towards personal health data being in the possession of for-profit corporations, but also the regulatory complexities of 'Big Data' and the potential privacy risks posed by data linkage.

It is clearly difficult to generalise about preferences regarding the secondary use of personal health data. This suggests a need for more nuanced ways to exert control over them. Given the potentially limitless use and re-use of electronic data, appropriate consent mechanisms need to be developed as well as ways to track who accesses personal health data. The foundation is a strong data governance frameworks and regulations. Technologies such as blockchain can also be deployed to enable better authorisation, control and transparency regarding what happens with data. For example, blockchain is beginning to be used (in Estonia, for example) to verify consent, and monitor access to personal health data.

7.5. Most countries are not using data to their full potential

Despite the willingness and desire of patients *and* citizens, and the availability of analytical and statistical methods, countries have been slow to deploy the potential of routine health data.

7.5.1. Countries vary in their capacity to deploy clinical data for knowledge generation

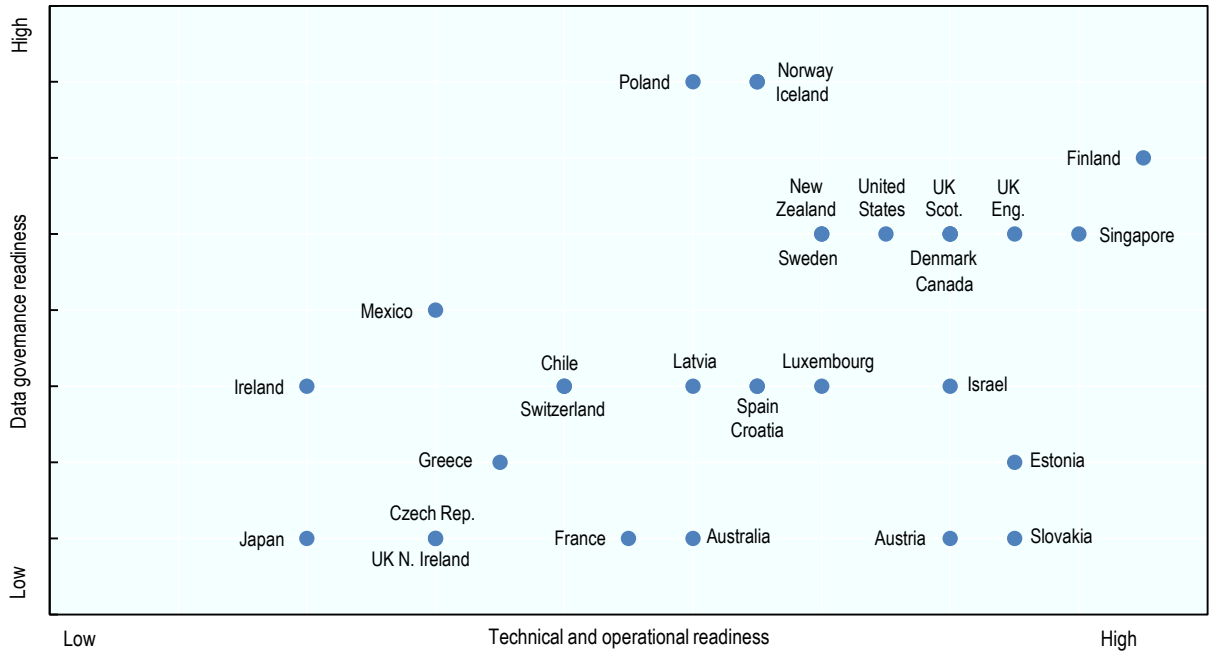
Clinical data collected in electronic health records (EHRs) present a potentially rich source of information and knowledge on the performance of medical products. EHRs are being adopted quickly in OECD countries (Figure 7.1). However, the technical and governance capacity of countries to harness these data for secondary purposes, including knowledge-generation on the performance of medical products, varies (Figure 7.3).

7.5.2. Countries report using routine data to inform policy in a limited way

A 2018 survey of 26 countries (including 23 OECD member countries) revealed that the majority collect routine data that contain information on the performance of medical products.[8] Surveyed countries reported that their routine health data are principally used to extract information on pharmaceutical consumption and aggregate spending (22 countries). Eighteen 18 countries reported using these data to monitor provider compliance, and 15 used them to track quality of prescribing. Meanwhile, 14 countries reported using routine data for pharmacovigilance (the safety of medicines) and 11 to evaluate their effectiveness (Figure 7.4). Routine data were less frequently deployed for the assessment of comparative effectiveness and cost-effectiveness, or to inform HTA and pricing decisions (OECD, 2019[19]).

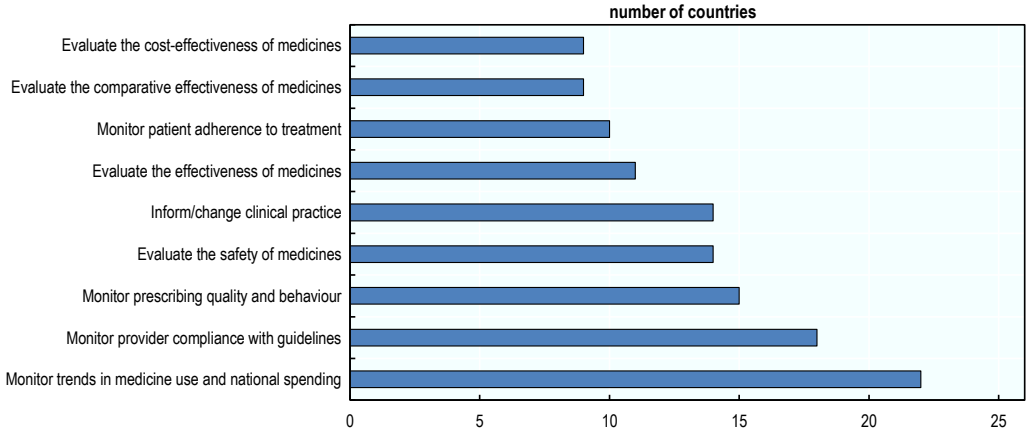
Figure 7.3. Countries vary in their preparedness to put EHR data to work

Data governance and technical/operational readiness to develop nation-wide information from EHRs, 2016



Note: Technical and operational readiness is the cumulative score of nine indicators each valued at one point: EMR coverage, information sharing among physicians and hospitals, defined minimum dataset, use of structured data, unique record identification, national standardisation of terminology and electronic messaging, legal requirements for adoption, software vendor certification and incentives for adoption. Data governance readiness is the cumulative score of four indicators: national plan or priority for secondary data use, dataset creation, and contribution of EHR data to monitoring and research which are each valued at one point; and legal issues impeding dataset creation which subtracts one point.
Source: OECD Survey of Electronic Health Record System Development and Use, 2016; Oderkirk (2017[13]) "Readiness of electronic health record systems to contribute to national health information and research", https://dx.doi.org/10.1787/9e296bf3-en.

Figure 7.4. Routine data are mostly used for monitoring medicine use, expenditure and compliance



Note: In most cases, the routine data described only cover medicines dispensed in the community setting and not medicines dispensed in hospitals.
Source: OECD (2019[19]), "OECD survey on use of routine data in pharmaceutical policies", https://www.oecd.org/health/health-systems/Using-Routinely-Collected-Data-to-Inform-Pharmaceutical-Policies-Analytical-Report-2019.pdf.

Importantly, the *extent* to which information derived from routine data is used to inform regulatory and other policy decisions was not assessed. While a growing number of retrospective studies using routine data are being published (with some examples outlined in Section 7.5.1), the extent to which this evidence is used to change policy and practice remains largely unknown.

Some national agencies tasked with regulating and assessing biomedical products are beginning to use the evidence generated by such studies in their decisions. For example, the Transparency Commission (CT) of the French High Authority for Health (HAS), which evaluates the therapeutic benefit of products, has in the past considered studies that used routine data to assess treatments for bladder cancer, exposure to acne medication during pregnancy and investigate the misuse of benzodiazepines. The latter resulted in a decision to reduce the drugs' reimbursement rate from 65% to 15%. In other countries, such as Germany, for example, responsible agencies are more reluctant to accept evidence that was not generated in prospective clinical trials (OECD, 2019[19]).

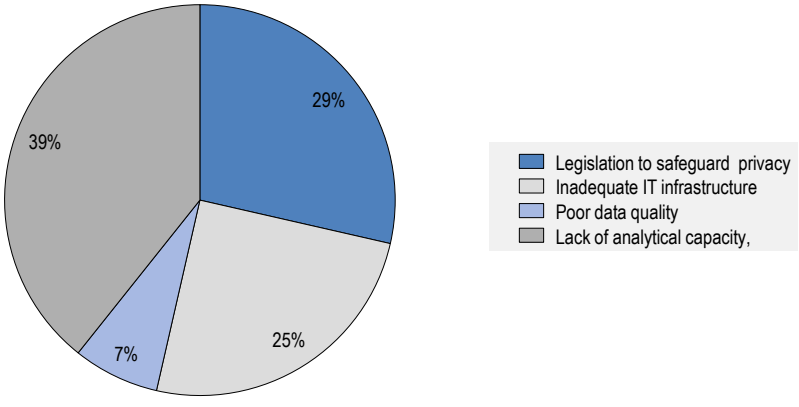
However, most surveyed countries (19/26) reported that routine data were *not used to their full potential* which suggests that there is still some way to go (OECD, 2019[19]).

7.5.3. The key barriers concern capacity, infrastructure and governance

Although some progress is evident, a range of challenges continue to inhibit the use of routine data for informing decisions in health systems. These challenges appear to be related to capacity, infrastructure and governance. Countries responding to the 2018 survey on use of routine data in pharmaceutical policy listed the following as the main barriers to harnessing these data: lack of analytical capability including human resources (39%); restrictions imposed by legislation to protect patient privacy (29%); inadequate information infrastructure (25%) and poor data quality (7%) (Figure 7.5).[9]

Reports of a lack of analytical capacity are noteworthy. The survey concerned only claims, administrative and prescribing/dispensing data, which are typically well structured and standardised. It did not include EHR data, which are more heterogeneous and unstructured. If there is insufficient capacity for the analysis of relatively straightforward datasets, then it can be assumed that this will be even more problematic for more complex data sources. It underscores the need to invest in capacity and human capital to put data to work in a productive and fruitful way.

Figure 7.5. Key barriers to using routine data for pharmaceutical policies concern analytical capacity, infrastructure and governance



Source: OECD (2019[19]), "OECD survey on use of routine data in pharmaceutical policies", https://www.oecd.org/health/health-systems/Using-Routinely-Collected-Data-to-Inform-Pharmaceutical-Policies-Analytical-Report-2019.pdf.

Similar barriers are reported for clinical data. For example, not all countries have, or are in the process of establishing, a comprehensive EHR system ("one patient one record") or an infrastructure that enables the sharing of information across various electronic platforms used by health care organisations and providers. The use of consistent minimum data sets and international data standards is increasing but deficiencies persist (e.g. data elements for surgical procedures or patient-reported outcomes) (Oderkirk, 2017[13]).

Some countries remain without unique patient identifiers, the absence of which make it very difficult to track care processes and outcomes longitudinally across cycles of care, providers and organisations. Lack of data quality and completeness is also common, problematic if they are to be used to complement high-quality evidence from RCTs (Oderkirk, 2017[13]).

Many counties also report legal constraints that limit their ability to use routine data for secondary purposes. For examples, health care provider organisations and authorities in many countries are only authorised to share EHR data for purposes directly related to care for the patient whose data are being shared. This makes secondary use to generate general knowledge from them impossible. Legal frameworks to protect privacy often also restrict the use of routine data to for research purposes (see also Chapter 8).

Another common challenge is a lack of procedural and institutional gatekeeping. This leaves stakeholders with insufficient clarity on who may lawfully access data, under what circumstances and for what purpose (Oderkirk, 2017[13]). Well-intended laws and policies, many of which predate digitalisation, can impede innovative uses of electronic data. With such problems precluding effective secondary use at national levels, creating a global ecosystem for the use of RWD will be extremely challenging.

7.6. Making better use of data requires concerted and coordinated policy action

Advancing the use of routine and RWD to improve the biomedical technology ecosystem requires action on a number of fronts and from multiple stakeholders: political leaders and policy makers, health care providers, researchers, industry, and patient groups and civil society. In the end, all stand to gain from the resulting approach to generating more advanced knowledge on medical technologies.

7.6.1. Countries must implement a governance framework the enables data use while maintaining privacy and security

The *OECD Council Recommendation on Health Data Governance* (the Recommendation), aims to help countries establish governance frameworks and infrastructure to enable learning through use of existing data. It lays out the fundamental elements for national frameworks and infrastructure (in technical as well as legal and policy terms) that enable the harnessing of real-world data for public benefit (OECD, 2019[47]).

The Recommendation asks governments to implement the technical requirements, not only harmonised data elements and formats and interoperability standards, but also state-of-the art cybersecurity methods. It also requires policies that minimise barriers to sharing data for various purposes – including research, regulation and other aspects of the biomedical technology ecosystem – in a way that maximises privacy, obtains informed consent where appropriate, and ensures compliance with other policy instruments such as the EU General Data Protection Regulation (GDPR).

The Recommendation also places considerable emphasis on transparency, public communication and stakeholder engagement – in an explicit acknowledgement of the central role of trust in establishing a new way of looking at and using personal health data (OECD, 2019[47]). In this regard, leadership is required to:

- Promote the benefits that can flow from putting real-world data to work, and thus shifting the discourse from using personal health data as a risk, to failing to use these data as the risk – in terms of the foregone benefits to individual patients and societies.

- Dispel the idea of a trade-off between data protection and secondary use of these data. It is not a zero sum game. In fact, a risk management approach and careful implementation of best practices and other mechanisms as described in the Recommendation can enable the achievement of both objectives.

7.6.2. Building and investing in capacity and infrastructure is key

A lack of analytical capacity and the necessary infrastructure are among the key barriers to realising the potential of routine and RWD in managing medical technologies. Countries must invest in the requisite capacity and expertise within the workforce to be able to manage and use these data in a secure way (a key aspect of governance), and apply the analytical techniques to extract valuable knowledge from them. Continued improvement to statistical and analytical techniques that manage bias and other inherent limitations of observational research methods also requires investment, in partnership with the research community.

Data need to be of sufficient quality and depth to enable good research to produce valuable evidence and knowledge. A key advantage of observational studies is their statistical power created by a large samples. This means that different types of data need to be linked and aggregated across jurisdictions, settings, agencies and organisations. In the case of rare diseases or precision therapies, data need to be shared between countries (see Chapter on cross-border data sharing). This requires investment in infrastructure that enables technical linkage, meaning that various data are encoded in a way that permits amalgamation and analysis. Developing common data and interoperability standards, as well as harmonising legal and governance frameworks, within and across countries is key.

Finally, generating complementary evidence from routine and RWD on how medical products perform is only the first step. Policy makers and other actors need to able apply this knowledge efficiently and meaningfully in regulation, HTA, pricing, and in clinical practice. This should also be a catalyst for further research. Relevant agencies must be empowered to apply the evidence in their decision making. Without policy to enable this, much of the effort will be wasted.

7.6.3. Other stakeholders also play an important role

Patient groups, as outlined above, have been vocal in their support for enabling secondary use of real-world data, and in this way have ensured that regulatory mechanisms such as the GDPR contain the necessary provisions that enable using personal health data for the public benefit.

Other stakeholders can play an important role. Civil society must be an active participant in this discussion, pushing for needed transparency in how data are used, how they are protected and what is then done with the resulting knowledge from their use.

The scientific community can reinforce the idea that using RWD is one way to address growing global health challenges by harnessing technological opportunities. Certainly one role for the research community is to make more apparent the risks of *not* using RWD to complement the clinical trial paradigm in addressing emerging concerns, ranging from the rise of chronic diseases as main public health issue to the inability of prospective research methods to detect rare events and deal with combination therapy. At the same time, methods and techniques used to extract knowledge from RWD must continue to be developed and refined to ensure that the evidence is of sufficient quality.

Payers, provider organisations and clinicians must play a part by recognising the secondary utility of the data produced during their daily processes. For example, for EHR data to become a valuable resource for research and policy, clinicians must embrace the electronic records not only as a key component of clinical practice but also of health system infrastructure. In turn, ensuring that all real-world data are of sufficient quality and can be pooled with those of other systems or platforms (this includes lowering the burden of entering EHR data) is a shared responsibility of industry and developers, provider organisations, payers and governments.

7.6.4. All stakeholders stand to gain

A health system that uses RWD to generate complementary knowledge benefits the entire biotechnology ecosystem. Patients are the principal beneficiaries from access to more beneficial, targeted therapies and information on their optimal use. Health professionals and providers will have better information to guide their decisions, and to discuss relative risks and benefits of treatment with their patients. The decisions of regulators, HTA bodies and payers will be informed by more robust, cumulative evidence of safety, effectiveness and cost-effectiveness, potentially avoiding high-publicity safety scandals or controversies regarding the pricing of treatments. The improved efficiency of policy and pricing decisions based on real-world evidence will be of benefit to society, with a view to getting the most value for its investment in health care.

Finally, the research-based industry will also gain through better identification of target populations and demonstration of value, as well as richer information to guide upstream R&D through, for example, more accurate evidence of unmet needs and identification of biomarkers.

7.7. Conclusion

The traditional model of separating research from practice, relying almost exclusively on prospective trials to create evidence on the performance of medical products is under strain. It limits the ability to translate scientific progress into new and better treatments for patients. It will also not enable policy makers to make increasingly complex decisions on regulation, financing and pricing, or patient care.

A new approach is needed, in which evidence from prospective research – which will remain the gold standard for generating evidence on safety and efficacy of new products and therapies – is complemented by knowledge created from routine and RWD. Such a model of continuous and iterative learning is now within reach given the rapid digitalisation of health systems and the development of attendant technologies and techniques to manage and makes sense of the growing volume of available data. The approach has been applied in other industries but some noteworthy examples in the health and biomedical research sector are emerging.

Yet overall progress has been slow. Systematising this new approach will require concerted action from policy makers and other stakeholders. The requisite capacity, data governance and infrastructure must be created to allow routine data to be put to work for this purpose, and for the resulting evidence to be effectively deployed in all parts of the technology ecosystem – from research and development, to regulation and pricing, to clinical care. This requires investment and partnering with other stakeholders.

Patient groups, civil society, the research community and industry must also play their part. A coordinated effort and international cooperation is required to ensure resources are available, uncertainty and associated concerns about the adoption of new research techniques and methods are addressed, and data and information can be shared within and across countries. This will increase the speed of implementation of an approach to managing medical technology that is more suited to current challenges, from which everybody stands to benefit.

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Notes

[1] This follows extensive laboratory and pre-clinical R&D.

[2] Probability of no events observed in 1 000 consecutive cases = $(1 – 0.001)^{1000} = 0.999^{1000} = 0.37$

[3] It must be acknowledged that regulation, global cooperation as well as economic levers such as competition have been important factors in these advances.

[4] Privacy issues are examined in a following section.

[5] Canagliflozin, which belongs to a class of drugs called sodium glucose co-transporter 2 inhibitors (SGLT2i), other SGLT2i drugs, and non-SGLT2i drugs.

[6] The database covers roughly 30% of the population of the Republic of Ireland, accounting for 74% of state expenditure on medication.

[7] See chapter on cross-border data sharing for more detail.

[8] The study focused on pharmaceutical products. The scope excluded electronic medical records.

[9] More than one response was permitted.

8 Intelligent system governance, stewardship and resource allocation

Martin Wenzl and Luke Slawomirski

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[1]). 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 priories.

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

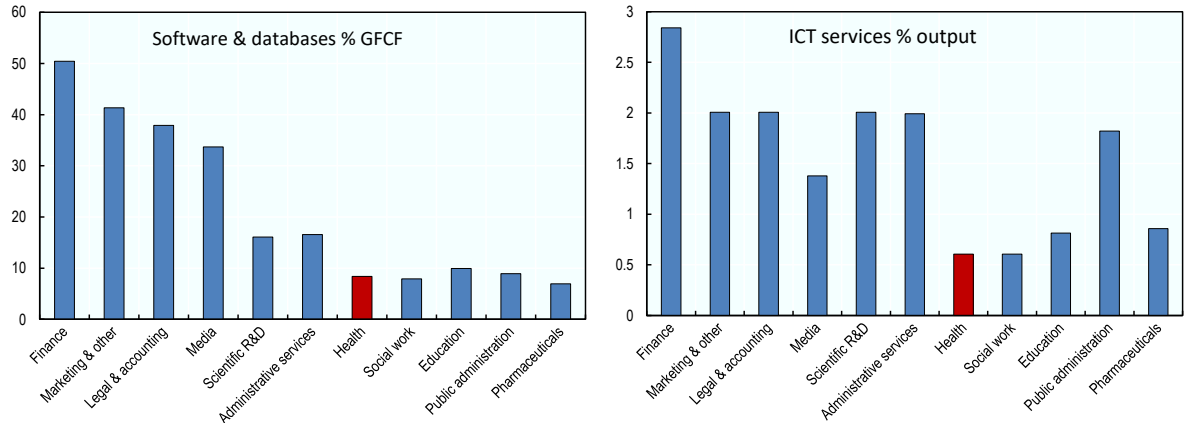
Source: Adapted from Bates et al. (2018[7]), "Why policymakers should care about "big data" in healthcare", https://doi.org/10.1016/j.hlpt.2018.04.006.

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 (GCFC) 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.

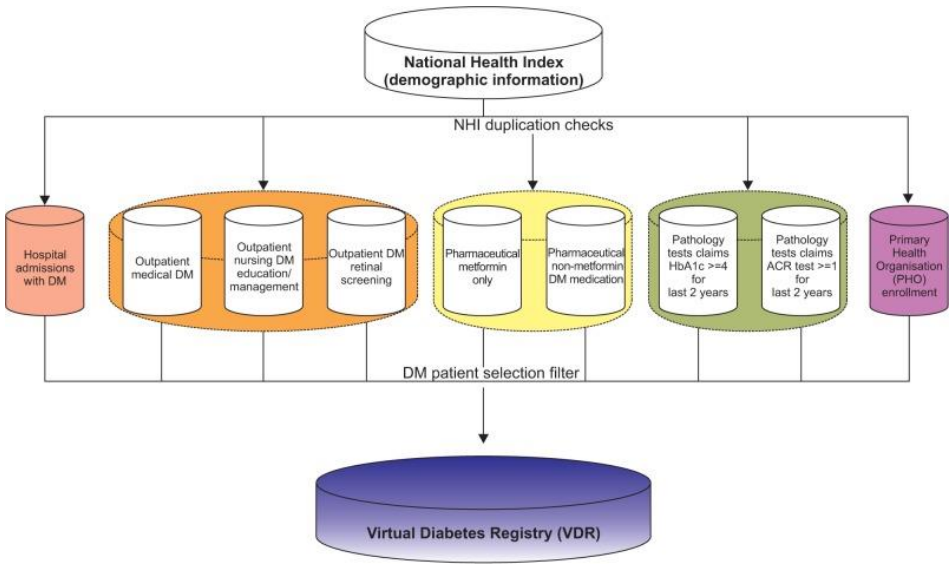
Virtual registries: a very efficient way to generate valuable knowledge

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.

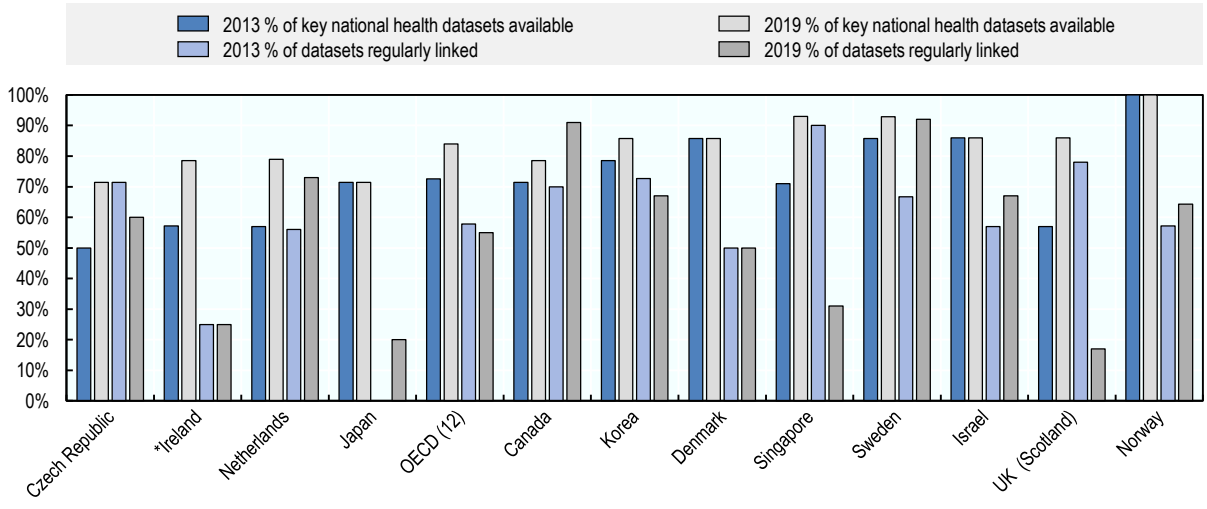
Routine data and their linkage enable more informed and responsive policy

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 England[6] 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 website[8] 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 Kinzigtal* 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 Kinzigtal, 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 Kinzigtal 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 Kinzigtal" in Germany", http://dx.doi.org/10.1007/978-3-319-25226-1_2; Lupiañez-Villanueva and Theben (2014[35]) "Gesundes Kinzigtal (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 been 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 expended 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]).

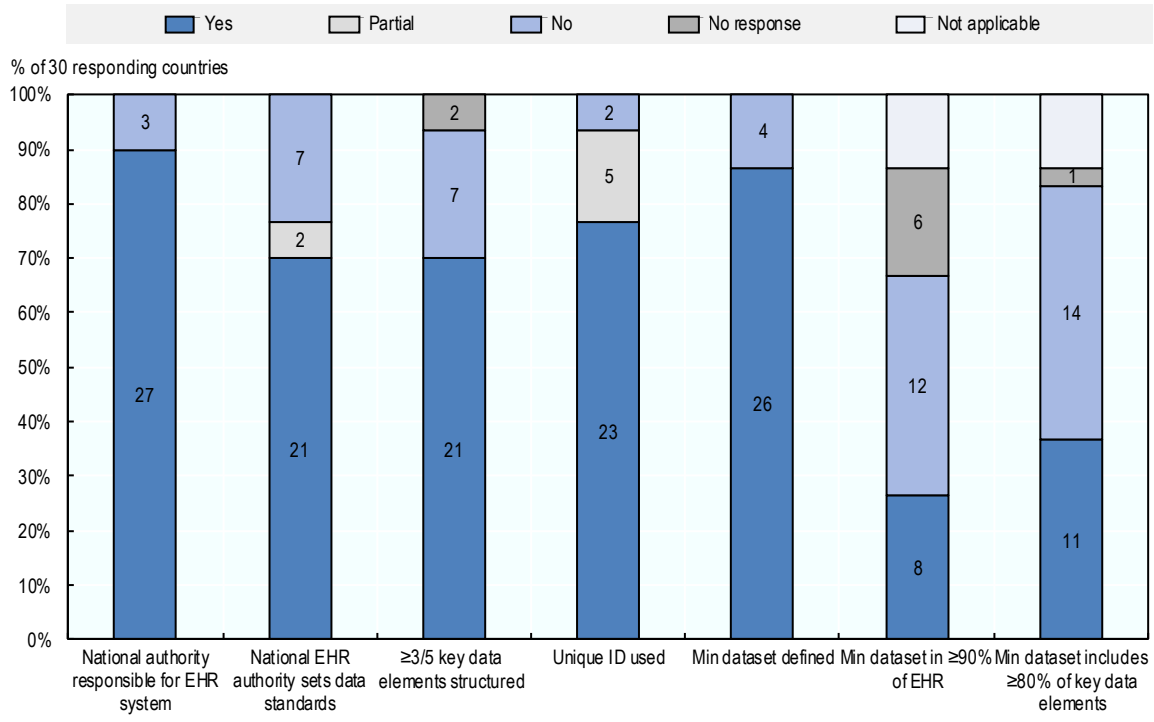
In a way, digitalisation is highlighting longstanding problems and challenges in health systems, such as fragmentation and a lack of institutional alignment and cooperation. But it also presents an opportunity to finally address these. However, while advances in technology can help overcome barriers 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 EHRs[13] 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]).

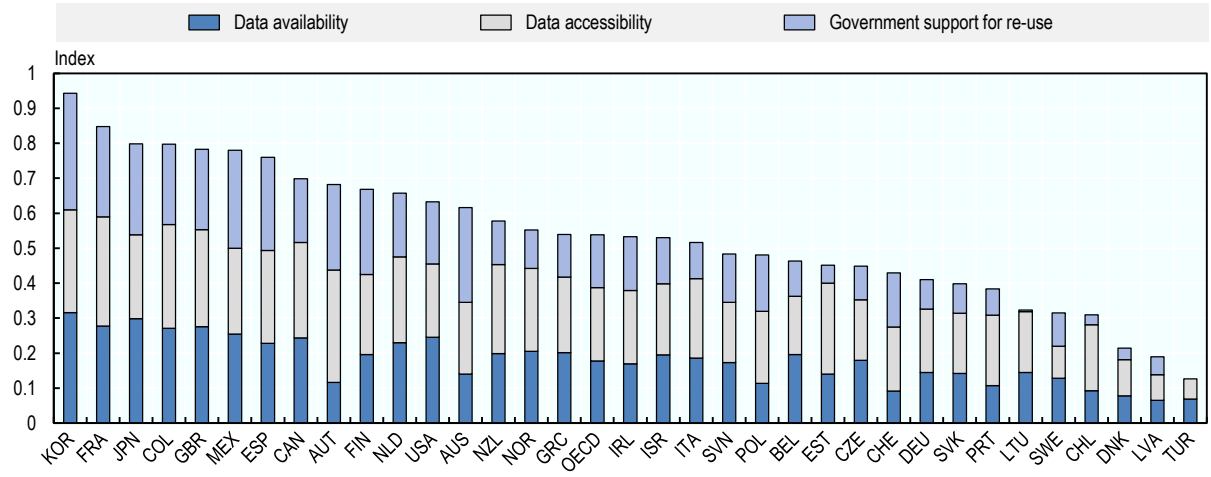
While the adoption of EHRs, the expansion of data collection and interoperability are all important prerequisites, they are only intermediate goals. If data are to improve health system performance, policy must create environments and conditions for effective use of data by all stakeholders, both in 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 accesses 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 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 gaols. 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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