3 The informed patient

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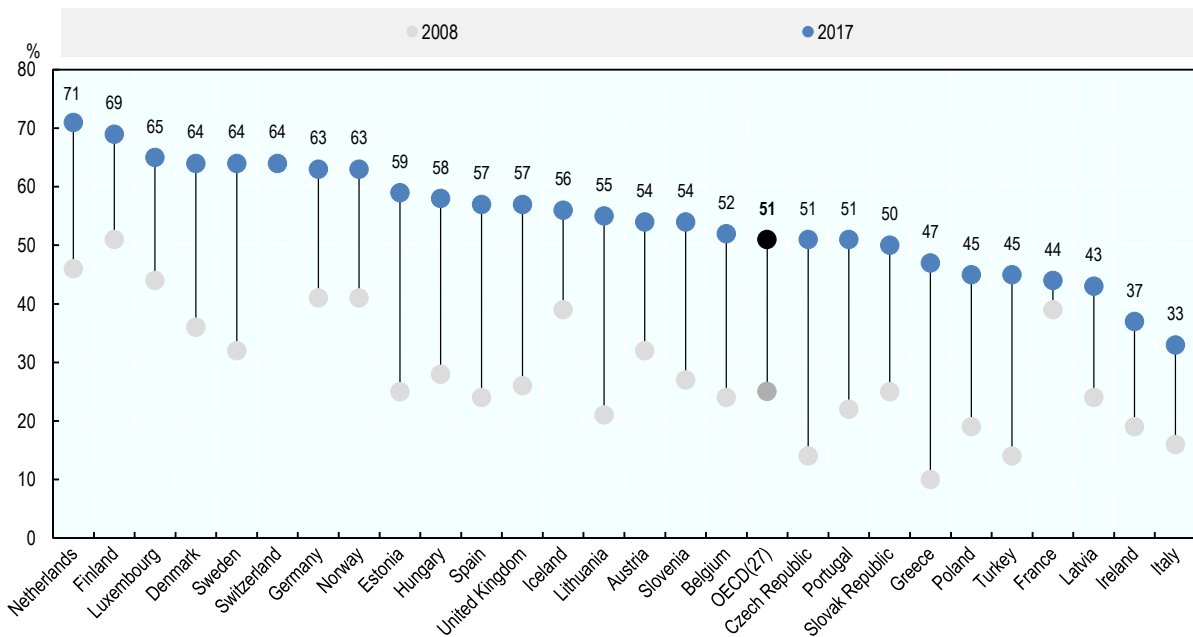
Source: OECD/EU (2018[27]), *Health at a Glance: Europe 2018: State of Health in the EU Cycle*, https://dx.doi.org/10.1787/health_glance_eur-2018-en.

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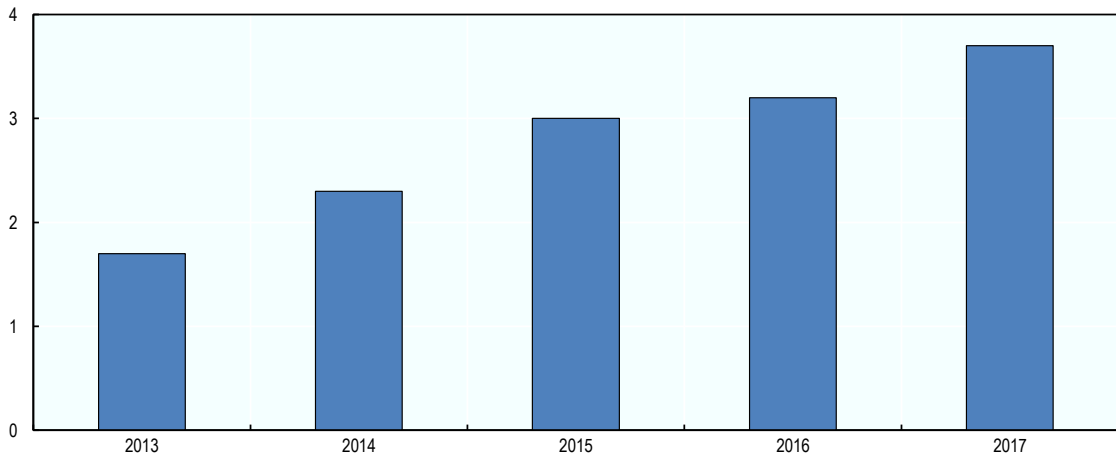
Note: Data for 2017 are preliminary estimates.
Source: Research2Guidance (2017[30]), "mHealth Economics 2017: Current Status and Future Trends in Mobile Health",
https://research2guidance.com/product/mhealth-economics-2017-current-status-and-future-trends-in-mobile-health/.

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

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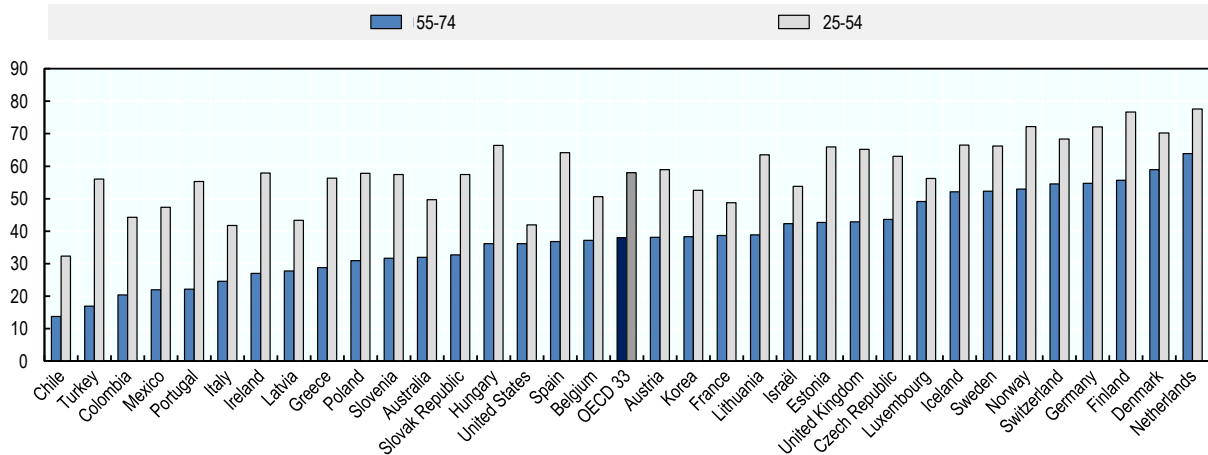
Note: Data for Chile, Colombia, Israel, and Switzerland refer to 2017. Data for Australia refers to 2016. Data for the United States refers to 2015. Colombia was not included in the OECD average as it is still officially in the accession process.
Source: OECD ICT Access and Usage by Households and Individuals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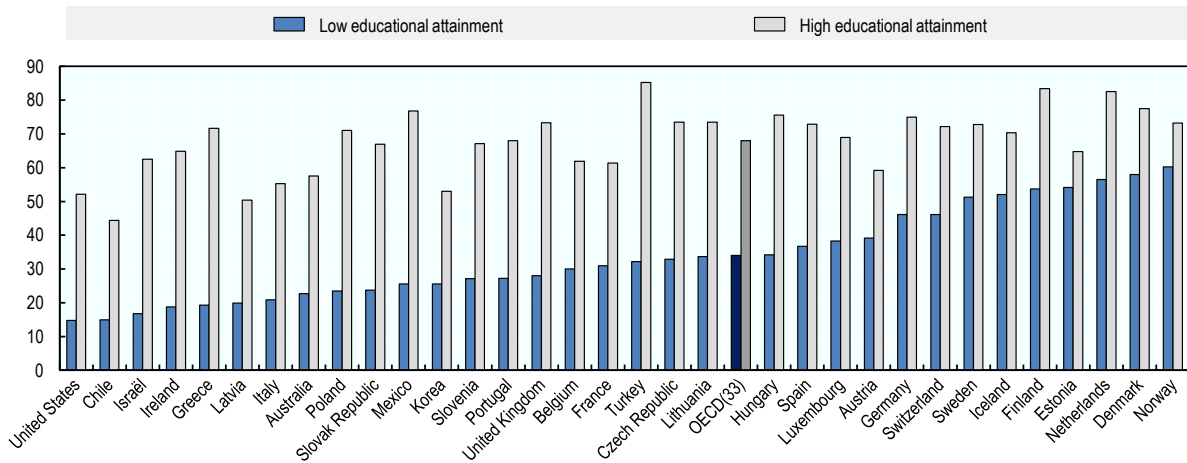
Note: Data for Chile, Israel, and Switzerland refer to 2017. Data for Australia refer to 2016. Data for the United States refer to 2015.
Source: OECD ICT Access and Usage by Households and Individuals Statistical Database 2019.

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.