Health in the 21st Century
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USING DIGITAL TECHNOLOGY TO MAKE HEALTH SYSTEMS MORE PEOPLE-CENTRED

• Smarter use of digital technologies and data can contribute to improve efficiency and effectiveness of health systems and make them more people-centered; in particular, they enable better targeting of services, co-ordination of care and communication, and engaging people in their health and their care. This is particularly important for the 40% of the population living with more than one chronic disease. However, the health sector is lagging behind other sectors of the economy in its use of digital technologies.

• Digital technologies can improve people’s management of their own health. The proportion of adults going online to search for health information in OECD countries has doubled over the last decade. However, they are often the healthiest people; vulnerable groups, older people and those with complex conditions all need assistance to use digital information better.

• Digital innovations are spreading across countries, but often without rigorous evaluation of their impact. Unlike in other sectors, effective, new approaches are rarely adopted and implemented at national scale. National strategies to evaluate, select and encourage the implementation of promising pilots are key.

Most industries are adapting to digital technology to transform and continually improve what they do. Consumers now benefit from products and services that are more tailored and responsive to their individual needs and expectations, more convenient and accessible, and which afford them more control and engagement. These industries have become more people-centred by innovating how they do things, using the opportunities of digital technology.

But the health sector lags at least a decade behind other industries in this regard. Different health services within a country still do not talk to each other electronically. Innovations taking place at clinical and service delivery level often remain local. The use of digital technology to deliver a better experience for people, to offer tailored services as part of a broader, co-ordinated package of care, to minimise duplications and be more efficient, is not yet the norm.
Innovations harnessing digital technologies in health – data-driven risk-stratification models, clinical decision aids, tele-monitoring and remote consultation systems, technology-assisted provider networks, communications infrastructure and electronic data – provide an opportunity for a similar transformation that other industries are undergoing, and improve services.

Health systems are now awash with electronic data. These data can be used to better identify specific health needs of individuals and population groups. They can help target preventive interventions at the most appropriate persons in the population and provide tailored care pathways to the growing number of people living with chronic conditions.

Digital technologies can also improve communication among patients and their care providers. They can improve choice and give patients better voice over their needs, thereby increasing the appropriateness and safety of care. In Spain, for example, the majority of the 17 regions have instituted integrated care models for patients with complex conditions. These people are first identified with a specifically-designed risk stratification model that mines electronic health record (EHR) data to assess their level of health need. Relevant patients are then provided with the necessary services and enrolled in care pathways tailored to their needs, enabled by electronic communication platforms.

The importance of people accessing their own health information cannot be overstated. Enabling access to clinical records helps make the patient a key member of their healthcare team. It enables self-management and encourages better co-production of health. For example, in Estonia a national patient portal allows people to easily access all of their health-related data and share their data with carers as needed, facilitating joint decision-making around care. The city of Oulu (Finland) provides an online self-care service enabling people to access their health information, add data such as blood pressure readings, and communicate with social and healthcare professionals. The platform is used by 29% of residents, including 39% of over-65s.

Digital technology also enables remote monitoring and service delivery, even in the patients’ homes. This cannot only be more efficient but can also support access, convenience and timeliness of care. Ontario (Canada) and Queensland (Australia) have invested in large-scale telemedicine services that make health care more accessible and reduce the need for more costly face-to-face care.
Digital technology has increased opportunities for people to access health information as well as health care information. For example, the number of people accessing health information online in OECD countries has more than doubled over the past decade. However, unless explicitly addressed, innovations often do not reach the most disadvantaged population groups, and may exacerbate health inequalities.

A challenge for governments is to ensure that the expanded access to health data and services offered by digital technologies is inclusive. Digital skills, health literacy and the ability to gauge good information from bad remain highly variable. For example, at least a third of residents of OECD countries, and over half in some countries, have poor health literacy. Inequalities are observed in a range of ways of how people use the internet, including seeking health information online (Figure 1).

The broader digital divide poses a risk of increasing existing health inequalities. Older people, those with lower education levels and from low socio-economic groups are less likely to display sufficient health literacy or engage in self-management care strategies.

Figure 1. Selected online activities by education level, 2017

The risks of widening access and health inequalities need to be managed. Some countries have designed programmes to better tailor information to the needs of specific groups.

For example, the IC Digital health literacy initiative in eight European countries developed modules designed for specific populations, including older adults, pregnant women, and people living with diabetes. Government efforts to enhance health literacy, particularly focusing on the capacity of vulnerable groups to access, use and interpret health information, need to be intensified as the digital transformation gathers pace.

SCALING UP WHAT WORKS REQUIRES A COHESIVE STRATEGY

The adoption of innovations from small firms to entire industries is a feature of other sectors on which health has a lot of ground to make up. Some innovations focus on narrowly defined patient populations, others have been implemented in relatively small provider networks sharing common information systems. However, rigorous evaluation of new approaches and their scaling up is rare. Among a recent sample of more than 100 European innovative, technology-supported care pilots for people with multiple chronic diseases, more than three-fourths remained local or regional and only about 40% were integrated into the wider health care system.

Addressing this requires explicit policy action and investment. Comprehensive digital strategies, with clear principles, priorities and targets, can create an environment and infrastructure conducive to innovation, where new approaches to service delivery are evaluated and, where appropriate, scaled up to the system level.

For example, Israel recently adopted a digital health strategy, making resources available for research, piloting and evaluation of projects and the improvement of information infrastructure. In Canada, a federal government entity tasked with promoting the use of digital technology in health care attaches the need for evaluation to all projects that receive funding. The United Kingdom has developed a vision for digital, data and technology in health and care. While many countries report having a strategy, comprehensive, system-level approaches to enable innovation, assessment and scaling are uncommon.

“New technologies are empowering healthcare professionals. Digitalization can free valuable time from routine tasks, allowing the staff to provide better, closer and more personal care for the patients.”

Magnus Heunicke, Minister of Health and Senior Citizens, Denmark

Questions for discussion

• What have been successful examples of innovative health service models that leverage digital technologies to improve care in your country?

• What are the barriers and bottlenecks preventing more rapid penetration and scaling up of innovative care models? How can these be addressed?

• What policies can ensure that innovative services leveraging digital technologies serve the interests of all people and communities in an inclusive way?

Note 1 - Using digital technology to make health systems more people-centred
TRANSFORMING THE HEALTH WORKFORCE TO MAKE THE MOST OF DIGITAL TECHNOLOGY

Note 2

- Unanswered questions about the legal and ethical consequences of decisions based on AI-produced information can also be a barrier to their use. Addressing these issues will require the development of new professional and ethical frameworks.

- Electronic data and digital technology hold great promise to help health workers address patient and population health needs. Examples include risk-prediction models or algorithms that flag diagnostic irregularities and customise clinical recommendations.

To take advantage, a health workforce must be equipped to use digital tools, and professional and ethical frameworks need to be modernised.

- The health sector employs 10% of the total workforce across OECD countries, but productivity growth has been low. Digital tools based on large datasets and Artificial Intelligence can help address increasing demand for health services by improving the effectiveness and productivity of health services.

- In order to realise this potential, health workers need to know how to use data and digital tools. However, 30 to 70% of all health professionals report gaps in knowledge and skills needed for a safe and effective use of digital tools.
Artificial Intelligence allows machines to perform cognitive tasks previously handled exclusively by humans. Across the economy, such technologies are likely to affect nearly half of all jobs in terms of their task composition, with one in seven jobs at a high risk of full automation.

Figure 2 presents 10 industries where jobs are most, and least, likely to be significantly automated. The health sector is among the least likely. However, many health jobs could see significant changes. Tasks that are repetitive, time-consuming, and heavy on data processing – selecting irregular results from pathology data or analysing patterns in patient outcomes for regular improvements in practice – are likely to be automated.

The resulting gains in productivity and effectiveness could address service bottlenecks and allow greater interaction with patients to address their needs more effectively, efficiently, and equitably. Successful examples are already emerging. Relatively simple digital tools such as the decision-support software for triage nurses in Emergency Care are in use, for example, in Australia, Canada and the Netherlands. These have significantly reduced costs and waiting times for physician consultations.

Other digital solutions contribute in particular to the effectiveness of prescribing, reduction of medication errors, and better co-ordination of care. In local pilot projects in the United States, digital tools allowed specialist (endocrinologist) care to be extended to all hospitalised patients with diabetes instead of only the most problematic cases, significantly reducing the rate of diabetes-related complications.
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, in particular AI. Even relatively simple machine-learning models already in use give rise to questions regarding health workers’ and machines’ respective roles, accountability, or about how to ensure that digital systems do not crowd out shared decision-making between patients and providers. For example, questions concern how to inform a patient when a risk-prediction model did not recommend treatment, or what mechanism exists to override the model’s recommendation, or again, what happens if following the model’s recommendation leads to a suboptimal outcome.

As the necessary ethical and professional frameworks lag behind, health professionals report hesitancy in using digital tools also due to a lack of insight into their design. Recent high-profile problems, such as incorrect treatment recommendations produced by IBM’s Watson in cancer care highlight the challenges. The current practice of digital tools being developed using hypothetical clinical data, and with little or no input from health specialists, must be adapted 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 and coding process.
Between 30 and 70% of health workers do not have all the skills they need to use digital technologies. In addition, some gaps in knowledge – such as understanding automation bias (favouring suggestions made by automated systems and ignoring other sources of information) or inherent limitations of data – remain largely unassessed.

Some countries are already making structured efforts to assess the skills demanded by digitalisation and to respond by amending education and training. Norway, for example, is restructuring national curriculum regulations in health to make these more future-oriented, and the United Kingdom has just completed a review of education and training actions needed to prepare its health workforce to deliver the digital future.

The Digital Health FACTS programme in Canada engages inter-professional faculty and students of medicine, nursing, and pharmacy to promote and scale up development of digital skills. Many countries have developed new programmes and accreditation standards in Clinical Informatics, with some creating hybrid degrees that closely tie clinical leadership with informatics and digital transformation.

More needs to be done, however, to ensure that the skills health workers need for effective and safe use of emerging digital technologies are taught routinely. Continuous Professional Development programmes also need to be updated. Furthermore, regulations need to allow for expanding or reassigning the professionals’ tasks and roles and recognising these changes in provider reimbursement models.

Questions for discussion

• What have been successful examples of health workforce transformation to use health data and digital tools more effectively?

• How has your country encouraged trust in data and digital technologies among health workers and addressed ethical and legal issues around their use?

• What has your country done to address gaps in health workers’ skillsets for the safe and effective use of digital technologies?
• When personal health data can be securely transferred, linked and analysed in a manner that protects individuals’ privacy, medical research, health system management and care delivery can be more effective.

• People must trust that their data are secure and used for purposes that align with societal expectations. This includes laws and policies governing control over, and access to, data, but also strong communication, stakeholder engagement and transparency.

• Getting the most from data requires them to be linked with other information within and, increasingly, across countries. For example, building knowledge on rare diseases or precise targeting of life-saving therapies require large, pooled datasets. However, linkage relies on developing common data formats and interoperability standards.

USING HEALTH DATA TO SERVE THE PUBLIC INTEREST

An astonishing amount of electronic data are produced every day. A growing proportion is generated by health systems through clinical, administrative, and financial activities as well as by patients themselves.

Electronic data can be used for different purposes at very low cost. This means that they can be leveraged to improve individual patient care (see Note 1), but also for a range of important secondary purposes. These include, optimising clinical processes and decision-making (powering the AI-driven innovations discussed in Note 2), monitoring health system performance, improving disease surveillance and public health, and supporting research to enable medical breakthroughs.

Putting data to work in these ways requires their sharing, linkage and analysis by third parties. However, personal health data are highly privacy-sensitive. People are also wary of third parties, such as technology companies, using their data without proper transparency and authorisation.

Excessive bias towards data privacy, though, hinders their secondary use. With the right governance, data can be kept secure and used for the beneficial purposes described above. The challenge for governments is to create an environment where personal health data can be used to generate valuable knowledge, and to ensure at the same time that individual privacy is respected. Leadership and transparency that explain the benefits of using health data as well as how risks are managed are vital.
The foundation for enabling secondary uses of personal health data is trust. Building trust requires more than protecting individual privacy, especially if this leads to failure to use data for better care and research. Trust involves engaging people and stakeholder communities in the process of developing policies and practices that govern how and when health data are used. It includes making these processes transparent.

Open public dialogue about potential benefits as well as the risks associated with health data – including the ways to manage these risks – promotes a balanced discussion. New Zealand has conducted a comprehensive public consultation around uses of health data, included public discussion on priorities informed by expert and policy input. The results guide decision around using data in a way that realises public priorities. This has paved the way for useful and cost-saving innovations such as building ‘virtual’ disease registries by harvesting patient-level data from a range of different sources.

Denmark undertook consultations on a strategy to serve the public interest through generating better knowledge from health data, and to make the national government, regions and municipalities accountable to the public for health data use. Australia recently undertook a broad public consultation around electronic health data. The results were incorporated into a new framework governing the secondary use of data within the national e-HR (My Health Record).

“Digital technology promises to make health services more inclusive, people-centred and efficient. But its adoption is lagging as it requires not only a digitisation of existing practices but also a more fundamental overhaul of the policies and institutions that govern health systems. This Forum aims to advance such a policy transformation.”

Angel Gurría, OECD Secretary-General

Managing who owns, accesses and controls personal health data – which include not just electronic health records but also, for example, administrative and billing data – is not easy. Individuals having access to their own data is different to owning all decisions about how these data are used. Monitoring of patient safety or infectious diseases will pose a societal risk if data are missing. In addition, data are often generated through activity funded by the taxpayer or other collective mechanism. This strengthens the case for health data as public goods and for using and sharing them to improve welfare for all.

Laws governing the ownership of personal health data vary across OECD countries. The EU General Data Protection Directive (GDPR) places personal health data in the highest security category but also acknowledges that some uses of these data benefit society and should be allowed. The GDPR guides countries to enact laws allowing personal health data to be used for public interest purposes with the necessary safeguards in place.

The OECD Council Recommendation for Health Data Governance – welcomed by OECD Health Ministers in 2017 – also recognises that data use must, first, have a legal basis and, where practicable, should occur with the consent of the individual. Online portals where individuals interact with their personal health information can be used to manage consent about uses of data in a more iterative fashion. This helps better engage the public -- who are generally positively disposed to secondary data use for public benefit – and mitigate problems of missing data.

The challenge is to determine under what conditions secondary use of data must be authorised by the individual. Particular sensitivity exists around access to personal health data by for-profit corporations. For example, the launch of the UK care.data initiative was criticised as access by commercial entities was allowed. In this context, strong engagement and transparency about the conditions for data use by primate entities and the safeguards for both individuals and societal goals become even more critical.

Note 3 - Using health data to serve the public interest
Health data are collected by different parts of the health system, stored in a variety of locations and managed by different entities. Bringing these data together increases exponentially the ability to use them in beneficial ways. For example, linking primary care, prescribed medicines, hospital admissions and mortality data would help monitor the quality of care of high-risk patients. Linking data on clinical trial subjects to their medical records would help understand performance of medical products beyond the window of the trial.

Figure 3 compares countries with regard to the (a) proportion of key personal health datasets available and (b) their regular linkage for secondary uses in 2013 and 2019. The preliminary results suggest that while countries are reporting a modest increase in the availability of key national datasets, less progress is evident in the regular linkage of these datasets for research and other purposes.

These preliminary findings signal the need to continue to address barriers and blockages for data sharing and linkage. One such barrier is the bias towards the privacy risks, as opposed to the opportunities of using these data, which creates strong laws not necessarily aligned with public goals and preferences. Another is the lack of common approaches to data terminology and exchange standards, which makes it difficult to share and diffuse data, digital tools and algorithms among health care organisations, within and across countries.

ADDRESSING BARRIERS TO THE SHARING OF HEALTH DATA

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Questions for discussion

- How has your country approached discussions about the secondary use of personal health data, including questions about data ownership, control and access?

- What have been the key challenges of using personal health data for secondary purposes such as research in your country? What are the positive lessons in your country in enhancing appropriate data access?

- Is your country actively engaging with others to advance the potential of cross-border data sharing?