

TOWARDS A ROADMAP FOR THE DIGITALIZATION OF NATIONAL HEALTH SYSTEMS IN EUROPE



Expert meeting Semmelweis University, Budapest, Hungary 21 June 2018

Division of Health Systems and Public Health



Towards a roadmap for the digitalization of national health systems in Europe

in the context of Health 2020 and the United Nations 2030 Agenda for Sustainable Development

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Abstract

On 21 June 2018, the Division of Health Systems and Public Health of the WHO Regional Office for Europe convened a first meeting to address the future of the digitalization of health systems. The one-day event at Semmelweis University in Budapest, Hungary, set out to identify stakeholders and strategic activities in countries currently digitalizing their national health systems; examine key actions in accelerating the process in Europe; and identify future priorities for action on digital health in the context of achieving the priorities of Health 2020 and the United Nations 2030 Agenda for Sustainable Development. This report provides a summary of the proceedings and discussions that took place, presents a future outlook for digital health, and outlines key areas, enablers, milestones and success criteria that participants identified for accelerating the digitalization of health systems in Europe.

Keywords

DIGITAL HEALTH HEALTH SYSTEMS DELIVERY OF HEALTH CARE HEALTH SERVICES ACCESSIBILITY HEALTH INFORMATION TECHNOLOGY eHEALTH EUROPE

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List of abbreviations

Al	artificial intelligence
DHR	Finnish Digital Health Revolution programme
EU	European Union
GDPR	EU General Data Protection Regulation
EHR	electronic health record
HIS	health information system
ICT	information and communication technology
NHS	United Kingdom National Health Service
SDGs	Sustainable Development Goals
WHO	World Health Organization

Note to the reader

The WHO Regional Office for Europe, through the Division of Health Systems and Public Health, together with the Ministry of Human Capacities, Hungary, launched the **digitalization of health systems** initiative on 21 June 2018 at Semmelweis University, Budapest, Hungary on the occasion of the 2018 Annual Conference of the European Health Management Association. This report provides a summary of the proceedings, presentations and discussions of the WHO Regional Office for Europe's meeting to launch this initiative. The report condenses each session, including interventions from the floor, according to the themes addressed rather than attempting to provide a chronological summary.

The summaries of the discussions and group work address the main themes emerging from wide-ranging discussions among all speakers, and do not necessarily imply consensus. Summaries of presentations and of points made in discussions are presented as the opinions expressed; no judgement is implied as to their veracity or otherwise.



Executive summary

Member States of the WHO European Region frequently employ digital technologies as part of reform initiatives to strengthen national health systems. These technologies contribute to improving the health and well-being of populations by extending the scope, transparency and accessibility of health services and information; improving service delivery; increasing health system efficiency; and empowering patients as part of a movement towards person-centred care.

Digital health is also important in achieving the public health priorities of the European health policy framework Health 2020 and the United Nations 2030 Agenda for Sustainable Development. It can strengthen efforts to achieve universal health coverage, change and improve modes of care delivery, and reform processes underpinning the operation of health systems. Digital health also offers essential solutions to important social and demographic stresses and global inequity issues, both now and in the future.

Policy-makers in the Region acknowledge the strategic potential and cost rationale for investing in digital health, and are now increasingly focused on digitalizing their national health systems. It is important, however, that this is done through a structured, intersectoral approach that engages stakeholders from across government, as well as nongovernmental organizations, civil society, academia, patient representative groups and the private sector.

To this end, WHO Regional Director for Europe Dr Zsuzsanna Jakab established a special initiative to facilitate the digitalization of health systems by providing countries with a fast-track, integrated approach to enabling digital health. In launching this initiative, the Division of Health Systems and Public Health, WHO Regional Office for Europe led by Dr Hans Kluge, convened a first meeting to address the future of the digitalization of health systems. The one-day event on 21 June 2018 in Budapest, Hungary, set out to identify stakeholders and strategic activities in countries currently digitalizing their national health systems.

In broad terms, the digitalization of health systems encompasses the establishment and ongoing maintenance of certain basic elements of infrastructure, including but not limited to hospital information systems, electronic health records and associated clinical support systems, electronic prescription and dispensing systems, telehealth and telemedicine (the provision of health care from a distance), registers and registries, mobile health, public health surveillance, and information portals for patients and health professionals. All of these elements can benefit from being linked through unique digital identifiers for citizens, health service entities and the health workforce.

However, for such infrastructure to operate effectively, appropriate legal and regulatory frameworks need to be in place. These must allow secure, interconnected, interoperable health systems to function while building upon appropriate trust relationships.

The meeting was successful in soliciting input towards the development of actions for accelerating the digitalization of health systems in European Member States, and in identifying future priority areas for action by WHO and its partners. The closing discussions identified a number of key themes that, although broad in scope, offer a strategic overview to guide future action, prioritization and funding.

Participants introduced the following core and emerging focus areas of digital health, and ensuing discussions provided a sense of their priority and importance:

- the standardization of data and related processes;
- the mobilization of external funding;
- the development of public-private partnerships;
- changes in the roles of established professionals; and
- universalism.

A number of probable future trends also emerged from the discussions, including:

- the overarching movement towards integrated, person-centred care;
- the advent of personalized medicine;
- the increasing use of patient-generated data;
- the changing roles and responsibilities of the health workforce;
- the need for new registers and/or registries; and
- the development of **new approaches/philosophies for data sharing** based on the above, coupled with mechanisms for capturing and managing the **informed consent of individuals**.

Most of these are attractive developments from the point of view of finance ministers. As such, they are additionally useful in advocating for or defending investment in core infrastructural elements and services of digitalized health systems. Countries require enhanced support to establish well designed building blocks for digital health systems in order to take advantage of innovations such as those listed above.

Finally, participants suggested that WHO could offer additional support by:

- working more closely with international partners such as the European Commission to define a **common regulatory framework** for digital health and telemedicine/telehealth services;
- championing person-centred care as a core value for digitalization;
- further anchoring digital health implementation in the achievement of key public health objectives;
- presenting **examples of progress** to counter the current complexity of discussions about digital health implementation (a result of the large number and broad range of stakeholders); and
- supporting the drive for clarity around the **core infrastructural elements and methodological tenets** of digital health through continuous monitoring, measuring and piloting to produce evidence.

Participants were united in their call for WHO to progressively scale up the initiative for the digitalization of health systems across Europe, and to take concrete actions to support Member States in establishing best practices in the design and implementation of their national digital health programmes.

Background

Digital technologies can strengthen national health systems by extending the scope, transparency and accessibility of health services and information, improving service delivery, and empowering patients as part of a transition to person-centred care. Digital health also plays a significant role in achieving the strategic public health priorities of the European health policy framework Health 2020¹, which advocates for strong intersectoral mechanisms to address risk factors and determinants of health, reduce health inequalities, and improve health and well-being.

The United Nations 2030 Agenda for Sustainable Development² and its Sustainable Development Goals (SDGs)³ reinforce and extend Health 2020 by seeking to build countries' capacities to achieve better, more equitable and more sustainable health and well-being for all. Digital solutions can help countries to achieve the health-related SDGs by strengthening efforts to achieve universal health coverage, disrupting and transforming the delivery of care, and reforming health systems' underlying processes.

Policy-makers in the WHO European Region acknowledge the strategic potential and cost rationale for investing in digital health, and are now increasingly focused on digitalizing their national health systems. It is important that this is done through a structured, intersectoral approach that engages stakeholders from across government, as well as nongovernmental organizations, civil society, academia, patient representative groups and the private sector.

As emerging technologies promise to transform the way health services are delivered, health decisionmakers are challenged to:

- understand the public health benefits and impact of emerging technologies as part of assessing their potential for adoption;
- ensure sustainable funding and demonstrate social return on investment for digitalization initiatives;
- engage and align digital health partners' efforts inside and outside the health sector; and
- ensure that core European health system values of solidarity, equity and universalism are not threatened as a result of the adoption of new technologies.

Approach

WHO Regional Director for Europe Dr Zsuzsanna Jakab established a special initiative to facilitate the digitalization of health systems. This is expected to provide countries with a fast-track, integrated approach to enabling the digitalization of health systems in order to strengthen health systems and public health, and to link investments in digitalization to meet national health policy objectives and key public health challenges.

To this end, the WHO Regional Office for Europe convened a first meeting to address the future of the

¹ Health 2020. A European policy framework and strategy for the 21st century. Copenhagen: WHO Regional Office for Europe; 2013 (http://www.euro.who.int/ data/assets/pdf_file/0011/199532/Health2020-Long.pdf?ua=1, accessed 19 August 2018).

² Transforming our world. The 2030 Agenda for Sustainable Development. New York: United Nations; 2015 (<u>https://sustaina-bledevelopment.un.org/post2015/transformingourworld</u>, accessed 19 August 2018).

³ Sustainable Development Goals [website]. New York: United Nations; 2018 (<u>https://sustainabledevelopment.un.org/sdgs</u>, accessed 19 August 2018).

digitalization of health systems. The one-day event on 21 June 2018 in Budapest, Hungary, took place in parallel with the 2018 Annual Conference of the European Health Management Association (see Annex 2 for the programme and Annex 3 for a list of participants).

Aims and objectives

The aims of the meeting were to:

- identify the main stakeholders and strategic activities being undertaken by European Member States towards the digitization of their national health systems;
- highlight the role and increasing importance of digital health in the context of achieving the priorities of Health 2020, universal health coverage and the health-related SDGs;
- examine the key actions required to accelerate the digitalization of national health systems in Europe, including mechanisms for assessing and adopting emerging technologies, reforming health-care access and delivery through digital health, empowering patients, and achieving health policy goals; and
- identify future priorities for public health action in order to develop a European vision and roadmap for digitalizing national health systems.

Expected outcomes

Expected outcomes of the meeting included:

- lessons learned from existing efforts to use digitalization as an enabler for the reform of health systems;
- a baseline of key actions for accelerating the digitalization of health systems in European Member States; and
- concrete proposals for public health action in formulating a roadmap for the digitalization of national health systems in the context of achieving the priorities of Health 2020, universal health coverage and the health-related SDGs.

Opening remarks

Attila Fábián, Deputy State Secretary of the Ministry of Human Capacities of Hungary, opened the meeting. He celebrated the opportunity to address some of the factors currently restricting the potential of digital health, and to help national health services incorporate the benefits of digitalization, including seamless integration and better-informed choices about care. He also commended WHO for focusing on this area and exhorted meeting participants not to let any idea go to waste.

Hans Kluge, Director of the Division of Health Systems and Public Health at the WHO Regional Office for Europe, emphasized the need to accelerate the uptake of digital technologies and emerging innovations into national health systems through three core aspects: inclusion, investment and innovation. Inclusivity requires leaving no one behind, in the spirit of the SDGs; investment must be strategic and sustained; and innovation that serves European values of universalism, equity and solidarity is critical. Free, frank and friendly dialogue around all these issues is of primary importance to progress.

Usman Khan, Executive Director of the European Health Management Association, underlined the theme of "making it happen". In this spirit, he described the possibility of digital health to provide shortcuts to the provision of care, and the opportunity for countries to shape the digitalization agenda to the needs of their citizens. This cannot be achieved in silos: progress must be based on the simple act of gathering people around tables and working in effective partnerships.

Miklós Szócska, representing Semmelweis University, Hungary, reflected on the importance of WHO taking up the digitalization agenda. The increasing digitalization of social life, banking and other fields is sure to happen in health care, and the preparedness of staff and systems is crucial to safeguarding patients' and citizens' trust. More generally, if Europe is unable to provide care though digital innovation, and then to export these solutions to the developing world, political and population pressures may mean that successive generations will be unable to enjoy the same quality of life that we do.

He noted, for example, that half of Africa's current population is under 20 years of age, and the continent's population will increase from 1.3 billion to 2.6 billion people in 20 years. For Africa to have even half as many doctors per person as Europe currently has, 2 million doctors will be required in 20 years, along with the money to keep them there. This illustrates the necessity of harnessing innovation to overcome enormous challenges. Learning, exchanging lessons and sharing inspiration is crucial.



The WHO Regional Office for Europe's initiative for the digitalization of health systems

The initiative for the digitalization of health systems is based on the notion that digital health is a key component of strengthening people-centred health systems. Its vision is to use digitalization to achieve the following goals:

- reforming health service access and delivery;
- empowering individuals to manage their own health;
- improving the efficiency and responsiveness of health systems;
- moving towards integrated models of care;
- achieving public health objectives; and
- ensuring that new technologies do not inadvertently contribute to social inequities (by increaing the digital divide), and that the core values of European health systems are respected and maintained.

Action is needed to define the components of health system digitalization and pathways to achieve success; to provide technical and policy guidance; to offer innovative support around digital health challenges; to advocate for stronger links between digital health and public and population health objectives; and to align the work of digital health partners inside and outside the health sector.

The expected outcomes of the initiative are fivefold:

- improved, integrated, more sustainable health systems;
- a movement of health care towards prevention rather than treatment, enabling individuals to take proactive roles in managing their own health;
- increased trust in and credibility of national digital health programmes;
- better use of digital health in achieving national Health 2020 priorities and the SDGs; and
- the inclusion of public health perspectives and requirements in the digitalization of health systems.

Intersectoral partnerships across all aspects of digitalization are required, as is concrete policy guidance that enumerates the requirements for success and how to fit them together. WHO is seeking to provide innovative support in this area, drawing on what countries are doing, channelling the work of partners, building a community to triage issues, and providing a safe space within a helpful community to share, assist with and resolve problems as they arise. A mechanism to demonstrate social return on investment is also needed to convince governments and financial decision-makers, who are often more focused on issues of efficiency than equity, of the value of digitalization.

Participants at the meeting were invited to offer guidance on identifying the components of an implementation roadmap for the digitalization of health systems, collecting and generating evidence for how technology is helping reduce the burden of disease in Europe, and linking existing initiatives to avoid duplication. The meeting emphasized that sharing experience, examining successes and learning lessons are the ground upon which to build future discussions. Input and feedback from this meeting will be refined through formal and informal consultation. Priority support areas will be identified and a number of initial outputs developed, and a stakeholder mapping exercise will be undertaken to identify potential partners. The initiative and its proposed actions will be communicated to all European Member States, and the implementation roadmap is expected to be presented to a Region-wide symposium at the Regional Office in Copenhagen, Denmark, in early 2019.

Public health action for accelerating the digitalization of health systems

The underlying values of European health systems are at risk in the face of the demographic and development stresses of the coming decades, and digitalization is key to addressing these stresses. At the same time, so-called digital colonialism is a concern, whereby telephones, computers and other devices continuously give information to collectors, sometimes outside of European domains. Such information-gathering carried out by the private sector – including the sale of data generated by individuals and public systems for research purposes that enable private profit – is often unchecked. An upcoming challenge will be to provide universal health coverage to the developing world without propagating this form of colonialism.

It is imperative to put data and digitalization into action, but crucial questions will have to be answered: Who should drive this process? How can interoperability work? How can we move beyond developing applications and devices for the wealthy to ensure that all benefit? A great deal of potential exists, from the powerful computers we carry in our pockets (more people in sub-Saharan Africa possess mobile phones than have access to clean water) to the prospect of Facebook drones providing free Wi-Fi in developing countries. In this context, it is more important than ever that Europe lead the way by developing strategies and sharing experience and best practice.

In Hungary, for example, where efforts to digitalize the national health system have been inspired by examples from Estonia and Scandinavia, data feeds digital maps, enabling the country to plan capacities, manage patient pathways and model access times. Based on the analysis of raw, diagnosis-related group data alone, the number of liver metastasis operations in Hungary increased by 40% between 2010 and 2016. This shows that lives can be saved using data that already exists, and that it is not always necessary to specify and scale systems to have a positive effect.

Raw data can also be used for auditing and compliance purposes. For example, when a pharmaceutical company threatened to pull out of Hungary unless its tax bills were reduced, an analysis of publication and co-authorship data related to diabetes care found that the number of doctors prescribing this company's products was 3–4 times that of those prescribing other products, suggesting some form of manipulation could be taking place.

Even data from outside the health system can be useful: for example, tobacco sales data have enabled targeted regional public health interventions. These processes have the potential to be automated and placed in the pocket of every doctor and every citizen. Overall, data and networking are of primary importance and value; equipment, sensors and interfaces can come later.

While it is important to prevent commercial developers and providers from driving this work and to avoid digital colonialism, some commercial tools have the potential to serve positive purposes. For example, an application that uses social networking data to detect depression can alert friends to warning signs, and be used for targeted, personalized public health interventions.

The institutionalization of this potential offers a world of possibility, and yet a large gap still exists between data and knowledge. Beyond the process of gathering data there is a pressing need for the necessary thinking and analysis, but ministries of health often lack these capacities. Unfortunately, the best, most capable technical and data specialists are often bought up by the private sector, leaving governments without the capacity to defend themselves against industry. Convincing governments to invest in this field, and in these people, is crucial.



Perspectives of national initiatives to digitalize health systems

Czechia

The 2018 priorities of the Ministry of Health of Czechia include: creating and/or amending reference registers to provide authoritative data for the identification of entities in the health system, and establishing their rights and responsibilities related to digital health; providing electronic identities for health workers; preparing the roll-out of fully fledged electronic prescriptions (e-prescription) and amending legal regulations accordingly; and establishing the National eHealth Centre to coordinate and support the development of digitalization and the national system of digital health. All of this action takes place within the framework of the Action Plan to Implement the National eHealth Strategy of the Czech Republic for 2016–2020.

Poland

Recent developments in digital health in Poland include: a national strategy to make the country's health system innovative, patient-friendly, more accessible and more secure; telemedicine plans to provide remote cardiac and geriatric consultations; and "hybrid remote rehabilitation" designed to provide comprehensive care after myocardial infarction.

Additional ongoing targeted projects will provide: e-prescription and electronic referral (e-referral) services; internet-based patient accounts that enable the exchange of medical data; an online platform providing medical entrepreneurs with digital services and medical registries (including of medical service providers, pharmacies, medicines, raw materials for medicines and coding systems); and a set of discrete systems for statistics in health care, evidence for health-care resources, hazard monitoring, integrated monitoring for the circulation of medical products, and monitoring of the education of medical workers.

Finally, following its Act on Information Systems in Healthcare, Poland plans to keep a set of national objective registries of strokes, fetal cardiac pathologies, salivary gland tumours, lung cancers, cases of Barrett's oesophagus and invasive cardiology procedures.

Belarus

In Belarus, where an integrated electronic health record (EHR) system forms the basis for a centralized digital health system, digital technologies have a positive effect on both patients' experiences and physicians' practices. To patients, the EHR system offers the ability to monitor health data; reduce inefficient visits to a doctor (for example, to obtain prescriptions); reduce the loss or misinterpretation of personal data; raise personal health literacy and awareness of health services; and more easily access health services through mobile technology. This makes patients active participants in the health-care process as well as assessors of service quality.

For physicians, the EHR system provides complete, reliable patient information from birth to death; access to the workplace from any device, regardless of location; a support system for clinical decision-making; increased time for face-to-face consultations with patients; reduced time spent searching for patient information; automatic preparation of reporting documents; and the ability to consult remotely.

Finally, health managers benefit from: reliable information about the state of public health and the quality of medical care; access to big data; enhanced information for prompt decision-making and flexible responses to identified issues; more effective financial control mechanisms; reduced costs for medical services and medicines; and reduced corruption risks. Overall, this promises to reduce mortality and increase life expectancy by increasing the availability and quality of medical care for patients; introducing quality management systems; and supporting clinical, organizational and management decisions.

Estonia

In Estonia, the legal and regulatory framework for digital health is based on several key principles: the duty of health professionals to send data to the health information system (HIS), access to the HIS by licensed medical professionals only, and the use of identification cards for authentication and digital signatures. The guiding strategy aims to use digitalization to increase efficiency, make expenditure outcomes value-based in order to offer better results for the same budget, and increase health research and development activity and entrepreneurship.

The HIS also ensures that patients have an opt-out system with the right to access and control health data through the Patient Portal, the right to delegate access to their data, the right to monitor visits and data usage, and the right to state intentions digitally (for example, for organ donation).

Privacy and security are founded on six main principles: secure authentication of all users with an identification card or mobile identification; digital signing or stamping of all medical data; maximum accountability and transparency; coding of personal data; an encrypted database that removes confidentiality risk from technical administrators; and monitoring of all actions and countermeasures. The future offers interesting additional possibilities for personalized medicine, clinical decision-making support and the use of big data.

Outcomes of this work suggest that the key to privacy is in citizens controlling their own health data, that data integration inspires economic growth, and that the principles of a digital single market should be put to work for the benefit of all European Union (EU) citizens.

Lithuania

Lithuania's model for digital health has been in development since 2009. Attributes include a central digital health system, an HIS for 150 health-care institutions, registers of medications and health institution licences, telemedicine and electronic booking (e-booking), and a patient portal. Connected health-care institutions now treat 90% of the country's patients, and 99.8% of pharmacies are also connected.

The overarching action plan runs until 2025, with individual development projects within it running for three years each. Plans for the next three years include further developing the e-prescription system; achieving national-level usage of the e-booking system for all institutions; improving integration of the system with other digital health processes; and linking digital health systems with family doctor services and home-based palliative care so that tests carried out during home visits can be automatically uploaded to the central system, allowing family doctors to issue treatments and medicines.

Other plans include psychological health data management in the central database, analysis of the database from a digital health perspective, integration with other digital health databases, and improving access to data and processes from mobile applications.

Discussion of country presentations to identify commonalities, areas of support and priorities for the digitalization of health systems

A short period of discussion revealed the following themes within the national presentations.

- Common elements of infrastructure around, for example, e-prescriptions, EHRs, integration and data sharing, underline the importance of basic legal, technical, and information and communication technology (ICT) infrastructure.
- External funding from the World Bank, the EU and others is often needed. Mobilizing funds for digitalization is a key issue.
- Advancement in digitalization will mean changes to the roles of established professions, and will require higher levels of analysis and support. Human resources must be adequately trained and prepared for this transition, and countries must manage and govern it appropriately.
- The European Commission provides considerable financing for cross-border projects, mostly of a research nature. While this investment is important, it continues to be difficult to leverage the outcomes of the many European Commission project-based initiatives. Some feel that funds are not adequately invested in solving real problems (such as facilitating communication among specialists).
- Policy-makers must be convinced of the strategic importance of the digital health ecosystem.
- The reluctance of physicians to take part in peer-review processes is a common problem.
- Understanding countries' core challenges requires deep investigation, and not just the examination of large-scale political issues. Changing laws and solving interoperability problems are relatively easy; it is more difficult, yet necessary, to change people's minds.
- Countries across Europe have now attempted a range of digital health implementation methods. Priority subjects should be reviewed in the beginning of the implementation process – for example, what should be hidden or restricted, and what areas of any given system will continue to require printed documentation. A movement towards a global digital health system is desirable, especially in terms of interoperability.
- Wasted public funding for health is a serious issue. A strategic approach to digital health that uses big data and engages third-party ICT professionals uninfluenced by major health-care stake holders could stem this wastage.
- Public engagement and trust are crucial. People have serious concerns (exacerbated by recent public incidents) and need to be convinced that their information is safe. Some possible advances (for example, implementing the benefits of whole genome sequencing) cannot work without incorporating big data into medicine and using it to inform individual care.
- The debate about digital health needs to move from a focus on data protection towards a more nuanced and sophisticated consideration of risk-benefit equations. The European Commission's General Data Protection Regulation⁴ (GDPR) may not provide the necessary regulatory framework to support the use of data as a medical asset.

⁴ 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). Brussels: European Council; 2016 (<u>https://eur-lex.europa.eu/legal-content/EN/TXT/?gid=1528874672298&uri=CELEX%3A32016R0679</u>, accessed 19 August 2018).



Future outlook on the digitalization of health systems

Digitalization in Denmark

Denmark has built a solid foundation for digital health: citizens have had unique personal identifiers since 1968 and digital signatures since 2003, and enjoy secure login to all public services. The country has a long tradition of health registries and databases, and based digital health on the pillars of a sound legislative framework and the Danish Health Data Network, which provides secure data exchange.

The Danish national electronic health (eHealth) portal provides access to personal health data from hospitals, general practitioners' offices and municipalities. It aims to provide a more coherent patient experience and to facilitate treatment locally, regionally and nationally. It logs 1.7 million unique users per month (a number that is increasing) and has been the dominant application for health professionals for seven years.

As well as secure access to personal data, the portal provides resources such as handbooks for doctors and patients, and a series of programmes on, for example, chronic disease management, quitting smoking and losing weight. Future plans for the portal are based on increasing the volume and security of data, improving the user experience, and incorporating user-generated health data from wearables.

Artificial intelligence (AI) in the United Kingdom's National Health Service (NHS)

A recent report from Reform, a think tank based in England, United Kingdom, entitled *Thinking on its own: artificial intelligence in the NHS*⁵, explains that while the current application of technologies in the NHS is piecemeal, a transformation plan is in place that intends to use AI to close gaps in health, quality, efficiency and funding. Yet a number of barriers related to data provision and access, ethical considerations, and trust still exist. This highlights the need for frameworks for the safe and ethical application of AI based on open standards, the digitalization of data and the monitoring of data quality, and user-centred design.

The report notes that it is a mistake to think about technology first; instead, work should progress from the problems/objectives/strategies and treat technology as a means to defined ends. Information legislation is best framed according to ease of access to information governance, and should focus on streamlining processes to foster confidence and trust. People and systems will evolve at different rates across a national system, and there will likely be periods of time when certain areas are more advanced than others. Countries can minimize this by ensuring that the basic building block of data – the EHR system – is in place.

Additional barriers include insufficient interoperability, issues with contracts with partners and providers, the fact that data are siloed and of varying quality, and the fact that a great deal of information in the NHS remains on paper in formats that are not machine-readable. In addition, the United Kingdom lacks unique personal identifiers, making data-linking difficult.

Resolving issues around trust, and particularly those that exist in the health sector, requires public buy-in

⁵ Thinking on its own: artificial intelligence in the NHS. London: Reform; 2018 (<u>http://www.reform.uk/publication/thinking-on-its-own-ai-in-the-nhs/</u>, accessed 19 August 2018).

to AI, an ethical framework and answers to ethical questions. These include questions related to verifying and validating new instruments (a task that can be especially challenging for live machine-learning tools that are by nature not fixed); minimizing bias; ensuring the transparency and explainability of results (for example, of how a neural net produces a result for a given data set); and ensuring accountability in case of failure. Simple systems get more buy in, as do technologies and products that feel relevant – they must be solving a real health system issue.

Public sector salaries are unlikely to be able to compete with those in the private sector, and while certain solutions can be developed in-house, some form of managed partnership with private entities will likely become increasingly necessary. It is also important not to undervalue the existing assets of the public sector – clinical expertise and data already in place are of great importance. Countries should consider opportunities to structure partnerships for maximum value to the public health system (for example, a public–private partnership model whereby a proportion of the revenue generated goes back to the public sector in perpetuity).

100,000 Genomes Project

Genomics England's 100,000 Genomes Project, which works to mainstream personalized medicine in the NHS, set out to sequence 100 000 genomes from around 70 000 NHS patients with rare diseases and their families, and those with cancer. They aim to increase subjects' access to information about their main condition or, if they are non-affected parents of children with rare diseases, to provide them with the option to access information about additional serious and medically actionable conditions and their carrier status.

As of June 2018, over 66 000 whole genomes had been sequenced and a semiautomated reporting pipeline was returning results to the NHS. By the end of 2018, the NHS will have a national Genomic Medicine Service caring for 55 million people and operating to common national standards, specifications and protocols for NHS care and research. It will deliver an approved national testing directory and set about building a single NHS genomic database to improve care, effectiveness and outcomes, and to provide de-identified data for academic and industry research. The lack of EHR interoperability in the United Kingdom does, however, pose obstacles to a national system.

Delivering on the four Ps of personalized medicine – prediction and prevention of disease, more precise diagnosis, targeted personalized interventions, and a more participatory role for patients – improves outcomes for patients. This can be achieved through technical advances and interventions that improve prognosis, allow diagnosis at earlier disease stages and therefore enable more treatment options, influence lifestyle factors, and allow for stratified medicine.

Yet this raises ethical questions, including about the use and handling of data and the capacity of data to predict outcomes. Advocacy must accompany technological progress, as people will often choose to take advantage of genomic technology if they are informed. Questions remain around the public health impact and cost–effectiveness of genomic medicine. While it has not replaced any other process, it is helping to drive change and, to a certain extent, refine and improve processes of change already underway.

An explosion of private firms are offering services such as ancestry testing, and there are cases of patients seeking procedures such as mastectomies based on false or mistaken data. As this tendency is unlikely to stop, health systems must incorporate the underlying technology in a safe and appropriate manner that takes a public health cost-benefit perspective. The 100,000 Genomes Project was an experimental, top-down, large-scale implementation rather than a gradual incorporation of a new technology; this method should be reviewed to ascertain if it has potential for application elsewhere.

Finnish Digital Health Revolution (DHR) programme

DHR is a large, four-year strategic research programme run by a multidisciplinary research consortium of Finnish universities. It studies "opportunities for a future person-centric health service ecosystem with modern data management models" with the vision of revolutionizing the future of health care to allow citizens to control and use their personal data. Current challenges include unclear legislation and regulation; siloed or poor-quality data that is not systematically managed; and a business environment not yet set up to share and use data effectively.

In this context, the My Data system, a Nordic model for human-centred personal data management and processing, attempts a paradigm shift in personal data management and processing. It seeks to move the focus of data management from organizations to people, making personal data a resource that individuals can access and control. DHR aims to provide them with the practical means to access, obtain and use their personal information, and to support health-care providers in developing new services using the data.

While the timeline for adoption is unclear, full operationality is likely two years away. Countries are conducting a great deal of work on cross-border data exchange, and as Finland is experiencing large health system reforms, no single leading organization has yet emerged to take the operator role and build the platform.



Digital health in practice

Person-centred care for patients with chronic conditions and multimorbidity in Norway

Challenges remain in administering care in large, sparsely populated territories, where it can be easier to call a helicopter than to collaborate around a patient and where care can be fragmented, reactive and inadequately person-centred. In this context, the Norwegian research project "3P – Patients and Professionals in Partnership" provides a roadmap to a digitally supported, person-centred, integrated and proactive care system for those with chronic conditions and multimorbidity.

A holistic view of morbidity starts with the recognition of suffering as a threat to identity: "who am I when I cannot be or do what I love most?" Doctors' failure to consider this can result in medical interventions that, while technically adequate, fail to alleviate suffering (and can themselves become a source of suffering). The need for holistic approaches is increasingly pressing as populations age.

Innovative telehealth technology may enable care that is person-centred; is coordinated, proactive and planned; offers one point of contact for patients with long-term complex needs; supports multidisciplinary needs; assists patients in self-care, thus lessening the burden on professional services; and forms the basis for a learning health system.

Virtual Hospital project in Finland

The Virtual Hospital project in the Hospital District of Helsinki and Uusimaa, Finland, set out to enable fast, better-structured work in a top-level national university hospital environment in order to provide more person-centred care. It ultimately increased the quality and availability of care for all Finns while controlling time and costs. Run jointly by five Finnish university hospitals, the Virtual Hospital is a digital service hub for specialist health care that provides services to all citizens and health professionals. It includes the Health Village, an online platform for patients, their families and health professionals that hosts over 30 hubs and 90 care pathways for dozens of patient groups.

A number of factors have been key to the project's success: clinics own and steer content, making the digital hub more like a transformation of existing operations than a new ICT project; the hub was built by a multidisciplinary team with a solid understanding of the service architecture; patients participated in the development process; and the project uses a collaborative approach to work, development and research.

The project aims to achieve improvements in seven areas: better decision-making support and standardized workflows; more proactive, targeted care; quicker access to specialized care; better-coordinated care and unified patient views (integrated care pathways); increased availability and quality of online training and self-help tools; a heightened sense of control on the part of the patients over their care process; and more efficient use of resources. According to the forecast model, these virtual services will free up capacity, saving €316 million annually by 2021.



Discussion of future outlook and digital health in practice: key areas, enablers, milestones and success criteria for accelerating the digitalization of health systems

The meeting concluded with a plenary discussion that drew on all the presentations to identify a number of themes (see Annex 1 for a visual presentation of themes). Discussions are summarized below.

Establishing core infrastructure and services

The digitalization of health systems requires the establishment of certain basic elements of infrastructure in the following areas:

- e-prescription systems;
- e-referral systems;
- mobile health for routine access to personal health records and delivery of health promotion/behaviour change activities;
- telemedicine and telehealth systems, perhaps initially for specific conditions and populations;
- digital registers and registries;
- standardized, codified and/or structured health data (including metadata);
- legal and regulatory frameworks (the 20th-century vision of privacy may be incompatible with the need to make information accessible in order to improve health outcomes, and with the need for truly interconnected, interoperable health systems);
- ethical infrastructure and frameworks, including for consent, data protection and use of data;
- unique personal identifiers for patients, health professionals and health-care entities (for professionals, this will help resolve standing issues related to monitoring licensing across borders, which will in turn strengthen capacity for cross-border care and help ensure patient safety);
- clear methodologies, including patient pathways within digitalized health systems and methods of monitoring and evaluating digital health;
- approaches to the challenges of integrating multiple existing systems and projects;
- programmes for digital and health literacy for the public and health professionals; and
- portals for patients and health professionals that incorporate different sources of data and information.

The portals for patients and health professions will need to integrate sometimes very large numbers of organizations and/or data sources. This requires establishing the infrastructure, but also ensuring that all necessary elements are working together. A single local hospital may have 90–100 different systems, many of which do not function together effectively. Achieving the vision at a population level will therefore involve significant challenges.

In all of the areas listed above, it will be important to consider how systems work for patients, and to

visualize patient pathways before conceiving what to build or enable. It will also be necessary to address the implications for patients of having responsibility for their own data and their own engagement with the system.

Increasing understanding through data - standards and interoperability

The digitalization of health systems enables the gathering of new data as well as innovation in the use of existing data, but this requires the standardization of data and related processes. The better and more standardized the data, the more valuable they are for research and the easier analysis becomes. All of the tools mentioned throughout the meeting (e-referrals, etc.) rely on standardized data. While this is widely understood and has prompted discussion for over 20 years, little progress has been made on standardization even within the EU. Recent attempts, for example, to have EU Member States list the standards used in their existing processes with a view to identifying commonalities have been unsuccessful.

The issue is twofold: standards must be identified, and then they must be applied. Choosing standards may be difficult, and some prefer to wait for others to take action first before determining what works best. Even when standards have been selected, other crucial elements such as resources, governance or testing capacity may be lacking. Overall, interoperability should be addressed at the health-system level – not just in terms of data, but also in terms of policy and process.

Implementing biometric data for patients and health workers has the potential to solve many issues by simultaneously standardizing data and addressing issues of cross-border licensing and care. This can be done quickly with an open-source solution. The EU could address this as a strategic issue and help to encourage Member States towards interoperability, citizen-by-citizen communication, and the use of research and structural funds to encourage the development of common systems – thus mirroring at a technical level the model for policy interoperability on which the EU was founded. However, issues of trust and potential misuse need to be carefully discussed and addressed in advance if European populations are to fully accept the Region-wide interoperability of health data.

Public–private partnerships with industry offer further opportunities for work on interoperability issues. For example, some European telecommunications companies are becoming more interested in securing use of their communications channels than in selling hardware, and they need to understand what kind of data will be transferred on 5G networks. Partnerships for interoperability that do not entail conflicts of interest are possible.

In establishing infrastructure for digital health, it may at times be necessary to address problems at a very basic level. For example, unique personal identifiers may be needed to link structures and services for both citizens and medical staff. Many countries do not yet have this basic requirement.

Mobilizing external funding

Mobilizing external funding, and making it strategic and sustainable, is important across Europe. Most digital health interventions or services aim to improve quality and reduce costs, but many European systems lack a mechanism for ensuring that external funding is explicitly paying for quality. There is, therefore, a need to explore how to incentivize improved quality through financial intervention. Incentives could be linked to patient-reported quality outcomes as well as targets for objective primary care indicators.

Connecting various EU funds is also crucial, as the failure of different funding systems to communicate with one another is a recurrent theme of contention. A strategic approach is needed that invests in cross-border research; links other funds, such as the European Structural and Investment Funds and the Norwegian Financing Mechanism, under the umbrella of a coherent strategy; and links the efforts of the Connecting Europe Facility, Horizon 2020 and others.

Building understanding and engaging with resistance

Digitalization will mean changes in the roles of established professions, and hence a need to clarify ownership and responsibility for the services and care provided through new, innovative systems. Issues of resistance and trust will undoubtedly continue to arise, and will have to be openly and transparently addressed for groups of health professionals and the public. WHO is requested to have a role in managing such processes.

While health professionals may broadly resist mechanisms of peer review, this resistance is less likely if the mechanisms in question enable anonymity and are non-punitive. For example, a Hungarian programme in which general practitioners could view one another's quality indicators in a single area – prevalence of treatment for hypertension – encouraged competition between colleagues. Within 3.5 years, the relative risk of stroke in the project area decreased by 29%, and the risk of heart attack fell by 24%. In another example, general practitioners who initially resented being forced to join national assessments later enjoyed them because the process enabled them to follow the progress of their patients referred to hospital. While forcing frontline health workers to shoulder increased administrative burdens is to be avoided, well designed and useful solutions will be in demand.

It is also important to remain sensitive to the degree to which health professionals invest in their personal identities as health workers, which they may have taken decades to build. These identities can be threatened by new technologies and changes to the face-to-face, interpersonal aspect of health care. It is crucial that relationships are not destroyed in the process of digitalization. What planners and policy-makers perceive as small shifts may not be small to health workers. Development processes for digital health must closely involve both health professionals and patient representative organizations.

Identifying future trends

A number of probable future trends emerged from the discussion. These include:

- the overarching movement towards integrated, person-centred care;
- the advent of personalized medicine;
- the increasing use of patient-generated data (for example, data from wearables, patient input, or diagnostic devices implemented at home);
- the need for new registers (of entities in the system such as doctors, dispensing pharmacies, etc.) and/or registries (that data-track patients or specific populations through particular care pathways or conditions); and
- the development of new approaches/philosophies for data-sharing based on the above, coupled with mechanisms for capturing and managing the informed consent of individuals.

Most of these are attractive developments from the point of view of finance ministers. As such, they are additionally useful in advocating or defending investment in core infrastructural elements and services of digitalized health care.

Targeting specific populations

Universalism and universal health coverage embody the concept of ensuring equal access to health services for all segments of society and avoiding the emergence of social inequities. While universalism is a core value of the digitalization initiative, in a number of situations digital solutions are needed to target specific demographics of society (for example, for managing unstable long-term conditions or particular types of cancer, for providing access to remote populations, etc.).

How such initiatives are to be prioritized and linked to broader strategies for health system development remains an open question. Many technologies and strategic approaches can be progressively implemented

by initially designing them for specific complex cases and considering more gradual, wider implementation later.

WHO key actions

Participants offered the following suggestions for ways in which WHO could provide additional support.

- Work more closely with international partners such as the European Commission to define a common regulatory framework for digital health and telemedicine/telehealth services. Neither the GDPR nor the Medical Devices Directive⁶ mention digital health or telemedicine; they treat health data as a block, but these data are inherently different in nature.
- Champion person-centred care as a core value for digitalization. To date, health systems are built around professions and diagnostics, and this has caused fragmentation. Effective person-centred care reorients health care around the needs of individuals and patients.
- Further anchor digital health implementation in the achievement of key public health objectives.
- Present examples of progress to counter the current complexity of discussions about digital health implementation (a result of the large number and broad range of stakeholders).
- Support the drive to achieve clarity around the core infrastructural elements and methodological tenets of digital health through continuous monitoring, measuring, and piloting to produce evidence. Assist in creating, then holding, a strong, strategic methodological centre for this work, accruing high-quality data to support and inform it, and moving step by step – from condition to condition – towards a coherent framework for the eventual whole.

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⁶ Council Directive 93/42/EEC of 14 June 1993 concerning medical devices. Brussels: European Council; 1993 (<u>https://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX:31993L0042</u>, accessed 18 August 2018).

Closing

Clayton Hamilton closed the meeting, thanking all who participated and lamenting the short period of time for discussions that could have used a full week. He described the meeting as a springboard – the departure point for real change. He characterized the outcome of the discussions as a "roadmap to the Roadmap", and promised to circulate an outline of the next steps in advance of a regional meeting on digital health in the first quarter of 2019.

Annex 1. Mind map of plenary discussion





Annex 2. Programme

Morning session

Registration

Introduction and opening facilitated by Ledia Lazeri, WHO Country Office, Hungary

- Welcome by Attila Fábián, Ministry of Human Capacities, Hungary
- Welcome by Hans Kluge, WHO Regional Office for Europe
- Welcome by Usman Khan, European Health Management Association
- Welcome by Miklós Szócska, Semmelweis University, Hungary

Introducing the WHO Regional Office for Europe's initiative for the digitalization of health systems

• Clayton Hamilton, WHO Regional Office for Europe

Public health action for accelerating the digitalization of health systems – opportunities now and for the future

• Miklós Szócska, Semmelweis University, Hungary

Perspectives of national initiatives to digitalize the health system

- National perspectives from Czechia: Martin Zemann, Ministry of Health, Czechia
- National perspectives from Poland: Anna Golawska, Ministry of Health, Poland
- National perspectives from Belarus: Mikalai Ramanau, National Scientific and Practical Centre for Medical Technologies, Belarus
- National perspectives from Lithuania: Igoris Baikovskis, Ministry of Health, Lithuania
- National perspectives from Estonia: Melita Sogomonjan, Ministry of Social Affairs, Estonia

Plenary discussion of country presentations to identify commonalities, areas of support and priorities for the digitalization of health systems

Future outlook on the digitalization of health systems

- Danish eHealth portal: Morten Elbæk Petersen (presenting remotely), Sundhed.dk
- Presentation of the report "Thinking on its own: AI in the NHS": Eleonora Harwich, Reform
- The 100,000 Genomes project and mainstreaming personalized medicine in the NHS: Tom Fowler, Genomics England
- The Finnish Digital Health Revolution programme and My Data system: Maritta Perälä-Heape (presenting remotely), Centre for Health and Technology, University of Oulu, Finland

Afternoon session

Digital health in practice

- The Epital Care Model for delivery of integrated, person-centre care enabled by digital health and its role in the Norwegian research project "3P – Patients and Professionals in Partnership": Gro Rosvold Berntsen, Norwegian Centre for eHealth Research, WHO Collaborating Centre for eHealth and Telemedicine
- The Virtual Hospital applying specialized expertise and technology in hospital-based care in the Hospital District of Helsinki and Uusimaa, Finland: Liina Hemminki, Hospital District of Helsinki and Uusimaa Digital Health Village
- The impact of digitalization in primary care settings in Hungary: Katalin Dózsa, Health Services Management Training Centre, Semmelweis University, Hungary

Plenary discussion of future outlook and digital health in practice to identify key areas, enablers, milestones and success criteria for accelerating the digitalization of health systems

Plenary discussion towards a roadmap for the digitalization of national health systems in Europe

Wrap-up and conclusions

Annex 3. List of participants

Belarus

Mikalai Ramanau Clinical Decision Support Systems Specialist Republican Scientific and Practical Center for Medical Technologies, Informatization, Administration and Management of Health

Bulgaria

Martin Bankov Senior Expert National Health Insurance Fund

Czechia

Dagmar Veselá Ministry of Health

Martin Zeman Director Department of Informatics of the Ministry of Health

Estonia

Viljar Pallo Project Manager Health and Welfare Information Systems Centre

Melita Sogomonjan Project Manager Ministry of Social Affairs

Hungary

Attila Fábián Deputy State Secretary Ministry of Human Capacities

Miklós Szócska Vice-Dean Faculty of Health and Public Services Director Health Services Management Training Centre Semmelweis University

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Linas Kavolius Adviser for eHealth Information Technology Coordination and Implementation Ministry of Health

Poland

Anna Goławska Acting Director Department of European Funds and eHealth Ministry of Health

Romania

Corina Silvia Pop Secretary of State Ministry of Health

Slovakia

Miroslav Bdžoch Ministry of Health

Peter Blaškovitš Head National Health Information Center

Carlo Botrugno NSP Holder at Institute of Health Care Slovak Medical University

Jozef Kalužay Ministry of Health

Others

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Temporary advisers

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Katalin Dózsa Family Physician, Research Associate Health Services Management Training Centre Semmelweis University Budapest, Hungary

Morten Elbæk Petersen (remote presentation) Chief Executive Officer Sundhed.dk (Danish eHealth Portal) Copenhagen, Denmark

Nick Fahy – Moderator Senior Researcher University of Oxford Oxford, United Kingdom

Tom Fowler Deputy Chief Scientist Director of Public Health and Caldicott Guardian Genomics England London, United Kingdom

Eleonora Harwich Head of Digital and Tech Innovation Reform London, United Kingdom

Liina Hemminki Development Manager HUS Digital Health Village Helsinki, Finland

Mark Nunn – Rapporteur London, United Kingdom

Maritta Perälä-Heape (remote presentation) Director Centre for Health and Technology University of Oulu Oulu, Finland

World Health Organization

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Ledia Lazeri Head a.i. WHO Country Office, Hungary

The WHO Regional Office for Europe

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

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