SCIENCE|BUSINESS

Citizens' health

7 ways e-health can get better outcomes for patients across Europe

Report of a high-level roundtable debate organised in cooperation with the Estonian Presidency of the EU Council

Partners

EU2017.EE Estonian Presidency of the Council of the European Union

SCIENCE|BUSINESS Healthy Measures

TALLINN UNIVERSITY OF TECHNOLOGY

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Summary

On 16 October 2017 at Tallinn University of Technology, a high-level roundtable of patient advocates, medical doctors, scientists, industry representatives and policymakers came together by invitation of the Estonian Ministry of Health and Labour to discuss various ways to break down the firewall between doctors and patients around Europe. The conversation, held under the auspices of the Estonian Presidency of the EU Council, considered how digital innovation might have beneficial (as well as harmful) effects on both patients' well-being and health professionals' own practices. The group debated policies to help make the patient a partner in healthcare, to create an ideal healthcare system, and to stimulate e-health innovations that will lead to economic growth.

Participants at the meeting came up with several suggestions for the future:

1. Citizens need to control their own health data and care. They should have access to their personal health records from birth.

2. The mission of any care facility should be to reduce inequality in patient outcomes. Policymakers should concentrate on the institutions within their countries that are performing strongly on this goal, with the aim of standardising best practice.

3. Medical records need to be able to pass smoothly among hospitals and care facilities, public and private institutions and companies – both within countries, and across borders.

4. Accelerate the adoption of open technology standards in healthcare across EU member states.

5. Greater investment in better IT infrastructures, and smooth implementation of the new EU General Data Protection Regulation, will reinforce cyber security.

6. Some patients will require extra help to learn how to use digital tools, such as e-consultations and e-prescriptions. And it's not just patients: doctors and nurses need help adapting to new technologies, too. More resources are needed for patients and patient groups to stay on top of new patient-related developments.

7. New digital tools should not be a way of bypassing relationships between patients and doctors.

This roundtable was one of a series organised by the Science|Business Healthy Measures platform, a group of 15 organisations – universities, companies, not-for-profits and government agencies – created in 2016 to promote debate on how best to reform health systems through the use of data on patient outcomes.

Introduction

There is a relatively recent movement, propelled by new technology and the related rise of an information-sharing culture, which sees patients taking a more active interest in gathering, studying and sharing their medical data. Welcome to healthcare in the digital age, where smartphone owners can have access to their own doctors at the touch of a button, and where doctors can use the resultant data flow to fine-tune how they treat the individual patient. In this world, the data can help the patient and doctor together get the best health outcome possible.

As well as redefining transparency in the patient-doctor relationship, this new digital push is enabling a psychological transformation of the individual from a patient to a partner. Health systems across Europe are now being challenged to build systems that allow better communication and more shared decision-making. The focus has shifted away from the days of health systems storing, owning and managing all our health data. Patients increasingly want to see their doctors' notes and be owners of their own medical data. Many now see it as a civil right that should be recognised.

But while new technologies matter to patients, people and relationships matter just as much or more. More than anything, patients really do want to be treated as people.

In a high-level roundtable, hosted at Tallinn University of Technology on 16 October 2017, health policy experts and officials from around Europe debated how these changes will affect healthcare systems. They also suggested several measures which could speed this vital transformation.

Topics discussed at the Tallinn roundtable

> The patient as a partner

How do you engage citizens and empower patients to take up a relevant role in diagnosis, treatment and research? This is the ambition of different initiatives from Ministries, hospitals, universities, and companies across Europe and beyond. They are taking the 'patient as a partner' approach, dismissing the idea of professionals as the only ones responsible for healing.

> The ideal healthcare system

How can healthcare systems be re-oriented towards patient outcomes to make them sustainable? How can business and public joint forces? Experiences from some member states as examples of what works and what does not.

> Innovation in e-health will lead to economic growth

What economic benefits can we expect to see from better, more innovative e-health solutions? How industry is shifting to a model that focuses on value and outcomes delivered, both to patients and to health systems.

The European context

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We have to make our health systems better...

We are not complacent

”

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The problem is all understand the need to collaborate, but haven’t found the way

”

The Estonian EU Presidency wants to move faster towards simplified public e-services and formalities, making interactions between citizens and public administrations easier. It wants to accelerate the adoption of electronic identification and trust services. It wants to strengthen security and privacy of personal health data.

Estonia considers it essential to update the EU cybersecurity strategy and bring e-privacy regulation in line with today’s needs and challenges. And it wants to use e-health to advance a more inclusive and sustainable Europe. Advancing cross-border, protected personal data and harmonising health services will make it easier for all citizens, especially as they move around the EU.

“We have to make our health systems better,” said Marika Priske, secretary general of Estonia’s Ministry of Social Affairs, speaking at the roundtable. “We are not complacent.”

But this ambitious agenda requires several challenges to be overcome, at both national and EU level. To get public support for change patients and citizens need to feel it is they who are in control of their own data and treatment; the system needs to support the patients, and patients need to trust the system. But that’s difficult, if people worry about the security or use of their data as it moves around among different carers, experts and institutions. Another problem: adapting standardised e-health systems to the huge diversity of health practices – even within one region, much less across the entire EU. We may develop some excellent artificial intelligence systems for machine-assisted diagnosis; but how will the economics of that work if every hospital uses it a different way? And to advance e-health uptake across the EU, policy makers must contend with a great divergence in budgets, culture and systems from one country to the next. Some, like Finland and Netherlands, are well advanced; many others have barely begun.

“The problem is all understand the need to collaborate, but haven’t found the way,” said Ain Aaviksoo, deputy secretary general for e-services and innovation in Estonia’s Ministry of Social Affairs.

From left to right: Ain Aaviksoo, Deputy Secretary General for E-Services and Innovation, Ministry of Social Affairs, Estonia;

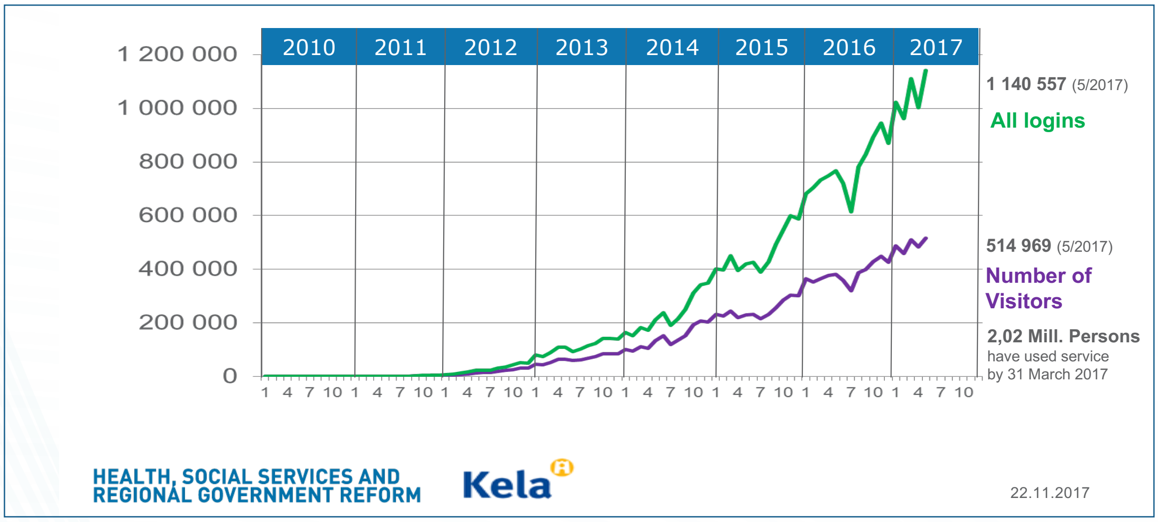
Monica Dietl, Senior Advisor, Science|Business;

Marika Priske, Secretary General, Ministry of Social Affairs, Estonia;

Jaak Aaviksoo, Rector, Tallinn University of Technology

Citizen-focused e-health developments in EU member states

The growth of Finland’s Kanta e-health system

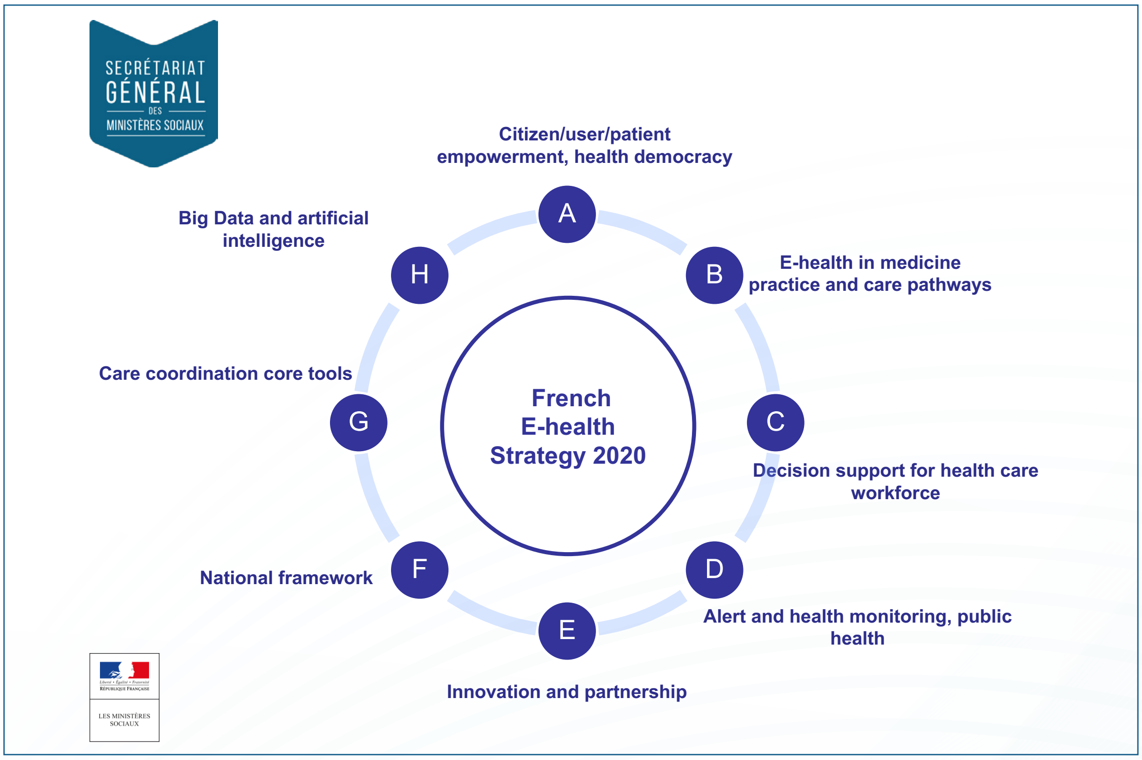


> Finland

The country has a well-regarded online one-stop shop service called ‘My Kanta Pages’ which allows citizens to view their health records, ePrecriptions and log files of data exchange. Through the website, Finns can also request a new prescription and consent or deny access to their records by a third party. Since launch about five years ago, more than 2 million people, out of a population of 5.5 million, have used the site. Coming soon: people will be able to enter their own health and wellbeing data into Kanta – connecting with various apps for home monitoring, smart diagnostics and fitness programmes. With consent of the patients, health professionals will be able to access that data – improving care. The system is part of a broad restructuring of the Finnish healthcare system that aims to improve the quality, equality and efficiency of care – and slow the growth of health expenditure.

> Estonia

The country is working with Finland on making patient records exchangeable between the two countries. The plan would make databases mutually available, thus facilitating cross-border access to digital prescriptions before progressing to full medical records. Specifically, Finnish e-prescriptions will be ready in 2018 for Estonian pharmacies to dispense; in 2019, Finnish pharmacies will be able to dispense Estonian prescriptions. Crucial to success of such a system – a boon to the thousands of people who travel regularly between the two countries – is that patients trust that their data will be accurate and safe.



> France

The country has had a nationwide scheme on electronic records since 2011, and a national strategy for e-health that aims for 2020 with a five-year investment plan of about €1 billion. The plan includes development of big data, artificial intelligence and care-coordination tools, as well as systems for health monitoring and decision support for healthcare workers. But despite strong political support, progress with implementation has been slow – due in part to the complicated organisation of France's decentralised health system.

> Poland

Public support is high in Poland for making the best use possible of shared health data; one survey found 80 per cent are willing to share their medical data under the right circumstances. And that's going to prove important for system efficiency, to cope with an expected 20 per cent rise in the economic burden of healthcare provision as the Polish population ages. But much remains to be done. Today, just one in four hospitals have introduced e-records. Less than 5 per cent of the population use any form of telemedicine. The country plans to move to full e-prescriptions in 2018 and introduce 'e-referral' facilities in 2019.

> The Netherlands

The government has a goal that at least 80 per cent of all people with long-term illnesses will have full online access to their medical histories by 2019 (and at least 40 per cent of other members of the population). But progress can be difficult. For instance, in 2009 the government launched one system to connect all health e-records across the country – only to have it blocked in 2011 by the Dutch legislature due to privacy concerns. Now, policies in this field are being developed, quite deliberately, in full consultation with patients and other stakeholder groups - so that there is agreement 'from living room to waiting room.'

Letter from the future

A patient of Blanca Usoz Oyarzábal, a doctor at the Biscay College of Medicine in Spain, recently wrote her a letter forecasting what the future might hold for doctors and patients. This is reprinted with the permission of the patient, Carolina Rubia Miner.

Dear Dr. Usoz,

The year is 2027 and I am writing this letter to tell you how I manage my chronic condition, how I interact with the health system and how I participate in research. I also want to let you know about the support among patients and specially introduce you to my health record.

Technologies already around in 2017 have ended up transforming health systems worldwide, thanks to the mind-set change and the transformation of the main health professionals' roles (including the patient). I hope that this letter will make us faster in imagining and designing a new health system, and especially in joining forces to achieve it.

I have a personal, vital health record. This record belongs to me – it's not exclusively linked to any specific health organisation, but it interacts with all of them.

My continuous glucose monitor sends information to the platform. Whenever my glucose level is low, I receive an alert and a suggestion to take corrective actions.

As you can tell, this vital health record gives sense to all those devices that were previously unconnected and it remarkably increases their value.

The personal vital health record came through a change in attitude a few years ago. Some patients and agents of the health ecosystem in Spain got together to design and build a platform that soon became universal, safe, and a place where citizens could keep their own integrated record.

The kick-off took place in 2017; when a patient coming from a so-called cluster for patient empowerment read a "letter from the future" to an audience highly involved in the transformation of the health system.

Back in 2017, public and private health systems and insurance companies became committed to building the better electronic medical records for patients. Before, each organisation thought that their medical record was the best.

Data standardisation and interoperability did not gain momentum until we started working on the universal vital health record. Until then, no organisation was interested in having their data shared with other institutions. "Data belongs to the patient!" they said, but the way that data was registered and extracted did not provide at all the interoperability and the information that we, the patients, needed.

Now, every new-born gets his vital health record where health data is registered from the beginning. This platform allows chronic condition patients and caregivers to be in contact with peers. Peer support is something that health systems have finally understood and incorporated as part of many treatments.

I no longer have scheduled visits to the endocrinologist. Our interactions, often in a virtual way, occur on demand.

The platform allows us to localise all the clinical trials that are taking place all over the world.

Today we can say that preventive medicine as well as diagnosis and treatment, are truly personalised. Our genetic and metabolic information is already loaded into our vital health record.

Surely, at this point you are thinking that this whole digital world has worsened human relations. But let's be realistic, we now have much more time for human interaction than we did 10 years ago. Now, thanks to the vital health record, many processes have been redesigned and digitalised, many inefficiencies and duplications within and between health organisations have been eliminated.

As you can see, things in 2027 could be very different compared to now. But don't forget these three points:

1. Technology available in 2017 already allows everything described in the letter.

2. Main challenges relate to mindsets.

3. No one will be able to lead the necessary transformation alone.

We have the capacity to transform current health systems into much smarter ones for everyone. Let's join forces!

Signed: Carolina Rubia Miner

The policy conclusions

1. Making patients CEOs of their health

Recommendation: Citizens need to control their own health data and care. They should have access to their personal health records from birth.

Patients in Europe need full and easier access to their medical information, according to several experts at the meeting . A concept promoted by Erik Gerritsen, secretary general in the Dutch Ministry for Health, Welfare and Sport, is that patients need to become the ‘chief experience officer’ of their own health records. “Everyone has the right to a digital copy of his or her data,” Gerritsen said. They, rather than any particular institution, should own the data, decide with whom they wish to share them and for what purpose.

> “*Everyone has the right to a digital copy of his or her data*”

Madis Tiik, an Estonian doctor and senior advisor for well-being at Sitra, the Finnish Innovation Fund, said that for anything that is relevant to his own health and wellbeing, he wants to be able to manage it himself. Tiik’s vision is for each individual or family to eventually be able to store medical data in a personal cloud or a digital wallet. Patients could then share their data however they choose: with family members, with researchers, with other doctors – or not at all.

Broader use of data and development of more user-friendly apps should help to put patients at the centre of their own care, with the doctor as essential adviser. These improvements can also allow e-consultancies, helping people who live in isolated places, reducing unneeded visits to the doctor and monitoring patients’ outcomes to alert them to the need to go to the doctor. In short, patients should be the CEOs of their own healthcare and health data.

Marika Priske, Secretary General, Ministry of Social Affairs, Estonia;

Jaak Aaviksoo, Rector, Tallinn University of Technology

Erik Gerritsen,
Secretary General,
Ministry of Health,
Welfare and Sport,
the Netherlands

2. Turning flowers into bouquets

Recommendation:
A mission of any care facility should be to reduce inequality in patient outcomes. Policymakers should concentrate on the institutions within their countries that are performing strongly on this goal, with the aim of standardising best practice.

> “
> *If we don’t invest more in the fertile ground, then we will have beautiful flowers but not a bouquet*
> ”

The argument for patient-centered thinking is that it will lead to more effective treatments and higher quality of life. It will also lead to more efficient use of healthcare budgets. By some estimates, around 25 to 30 per cent of health budgets could be wasted through inefficiency. There is a need to look at all of the costs and understand what interventions make a difference. Therefore, it is a priority to build a health-system framework based on analysing and acting on the data about patient outcomes, and the infrastructure to support it.

So far, where this kind of patient-focused approach has begun, the results are encouraging; leaders include the Swedish, Dutch, British, Finnish and (selected) parts of the US health systems. Indeed, such is the variety of approaches and experiences in Europe that “Europe is an innovation lab” for Amgen, said Herb Riband, the company’s vice president for international policy and government affairs. But this variety has downside, too: each system is usually working in its own silo, without sharing knowledge about how to optimise procedures.

Adoption of new cultures and technologies in health systems is not effortless, though; and many still face challenges. Less than half of all hospitals in Poland have introduced e-records, for example, and only around one in 20 people use any form of telemedicine, said Agnieszka Kister, director of European funds & e-health at Poland’s Ministry of Health (although a new e-health strategy should be launched before the end of this year).

There are differences between countries, but also within countries. It was agreed that policymakers should concentrate on the institutions within their countries that are best at using outcomes data to improve treatments, with the aim of standardising best practice across all care institutions and European-wide. Gerritsen said there were pockets of strong patient-centred care in the Netherlands – a recognised example of best practice is the Santeon healthcare group – that need joining up.

“If we don’t invest more in the fertile ground, then we will have beautiful flowers but not a bouquet,” Gerritsen said.

Cristian Grasu,
Secretary of State for
Health, Romania

3. Doctors without borders

Recommendation:
Medical records need to be able to pass smoothly among hospitals and care facilities, public and private institutions and companies – both within countries, and across borders.

The incentives for sharing data are beginning to fall into place in many EU member states; and medical centres are starting to make medical information more available to patients. Over the past decade, nudged by new laws, many hospitals and clinics around Europe have been converting written doctors' notes into electronic records. "Our idea in Finland is think 'digital-first'. It is very widely accepted," said Maritta Korhonen, ministerial counsellor at the Finnish ↱ Ministry of Social Affairs and Health. "In Finland, e-prescriptions are mandatory and all public and most private health care providers are connected to the national patient data repository."

> “*Our idea in Finland is think 'digital-first'. It is very widely accepted*”

The same holds in the Netherlands. "If doctors do not use modern ICT, they are not in line with government rules. Any personal health data must be useable and safe," said Gerritsen.

These new digital resources can translate into better health. The advent of e-prescriptions has made life "a lot easier for patients", said Anneli Habicht, managing director of the Estonian Chamber of Disabled People.

However, the vast majority of hospital systems still cannot easily (or safely) share their data. The dream for the European Commission is that e-prescriptions will one day be exchangeable across all member states. Together with 16 EU countries, the executive is crafting an eHealth Digital Service Infrastructure to enable the exchange of patient summaries from 2018. There are small pockets of bilateral cooperation already – like that between Finland and Estonia on e-prescriptions. This should spread to all of Europe, the meeting heard. Digital registrations in hospitals should be part of national systems, with access possible across EU member states through a Health ID number. If records can travel with the ease of emails, doctors in different locations can better dispense treatment, avoiding the need to repeat tests. Databases of clinical information make it easier to track outcomes in various disease categories. They are also gold mines for medical research. This crowdsourced data could help develop cures, discover new uses for drugs and better track the spread of new illnesses.

4. Open data standards

> “We have a big problem with data standards and quality. We must fix these things with policymakers”

Recommendation:
Accelerate the adoption of open technology standards in healthcare.

To help data travel more smoothly between care units and between countries, experts also call for an increased effort to accelerate the adoption of open data standards in healthcare. The problem is that many of the leading health software suppliers design electronic medical records on closed, proprietary systems, which tend to lock in customers.

“While digitisation is an important development, quality standards need to be considered too. We have a big problem with data standards and quality. We must fix these things with policymakers,” said Habicht, of the Estonian disabled patients’ group.

5. Patients worry about confidentiality

> “From May next year, big health systems will require data processors and controllers, which should ensure a level of security. There will be a new obligation to report personal data breaches”

Recommendation:
Greater investment in better IT infrastructures, and smooth implementation of the new EU General Data Protection Regulation, will reinforce cyber security.

Concerns about medical records remain, especially around privacy. There should be reasonable safeguards to stop private health information being stolen and trafficked by cybercriminals. In health centres, it is common for patients’ health records to be stored together in central databases that, once breached, yield a trove of information.

New data protection laws – the General Data Protection Regulation – coming into effect in May 2018 in the EU will require a higher level of protection, said Annabelle Bruyndonckx, counsel with international law firm Simmons & Simmons in Belgium. “From May next year, big health systems will require data processors and controllers, which should ensure a level of security. There will be a new obligation to report personal data breaches,” she said. Health systems must also ensure electronic health records are stripped of identifying details before they can be used for research. That requires more than simply removing a name; any information that might identify the patient must be scrubbed.

Anneli Habicht, Managing Director, Estonian Chamber of Disabled People (centre)

6. Help with digital tools

Recommendation:
Some patients will require extra help to learn how to use digital tools, such as e-consultations and e-prescriptions. And it’s not just patients: doctors and nurses need help adapting to new technologies, too. And more resources are needed for patient groups to stay on top of new developments.

Modern eHealth systems allow health professionals to better organise care around what patients really need. Almost everyone now has a mobile or a tablet; and people often prefer interacting with digital technology to visiting hospital. Some patients can now send in pictures or have a video conference call with one of their doctors or nurses. Information can be shared with general practitioners and consultants, who in turn can keep tabs on whether a patient might need to be seen. One relatively new technology mentioned at the meeting, known as a blockchain, is an encrypted data platform that could in the future give patients digital wallets containing all their medical data, continually updated, that they can share at will.

It’s important that patients be able to keep up with all these new digital tools. “A lot of patients are unable to use them, and we can’t forget them. We must think about blind patients, those with intellectual disabilities, and older people. They need help or they will be left behind,” said Habicht, of the Estonian patients’ group. Furthermore, not everyone is comfortable sharing all their medical information – although there is a feeling that people will increasingly want access to their medical data and will share it, especially younger people reared on social networks and smartphones.

> “*A lot of patients are unable to use digital tools, and we can’t forget them. We must think about blind patients, those with intellectual disabilities, and older people. They need help or they will be left behind*”

And things are changing fast. Already, many more patients are becoming more involved in healthcare services and policymaking; and today there are websites devoted to collecting and publicising patient ratings and reviews of healthcare professionals, services, diagnoses and treatments. This patient experience data highlights differences across providers, regions and over time. “We believe patients need to have actual control,” said Gerritsen of the Dutch ministry. A perfect illustration of people exercising this control came in 2011, when Dutch voters prohibited government from constructing a national patient data centre.

Yet many people still find it hard to speak the language of medicine; and sometimes the burden for patients to get informed is just too high. “Reading long documents about health policies and analysing them requires a lot of legal expertise,” said Habicht. To feel empowered, patient advocacy groups need more resources. What would also help is if patients received more accessible communication from health professionals. This means doctors should try to avoid using too much complicated medical terminology: “Only then can the patient be partners,” Habicht said. The effort pays off: better-informed patients are more likely to take better care of themselves, follow prescription drug regimens and even detect early-warning signals of illness, the meeting heard.

7. Digital tools must not replace bedside chats

Recommendation:
New digital tools should not be a way of bypassing relationships between patients and doctors.

> *“I often see a certain percentage of healthcare professionals who have an inherent scepticism or mistrust in the use of technology”*

Opening data to patients raises new challenges, however. Will worried patients engulf doctors with time-consuming questions? Doctors can find the shift complex to navigate too; many complain about the time it takes to update digital records. Some clinicians are reluctant to record patient-reported outcomes because they fear it will add to their workload; perhaps they feel they understand their patients’ problems already. “Developing a culture of trust in health systems is an important and often overlooked factor for success in digital adoption. While trust in health can be viewed from different perspectives, I often see a certain percentage of healthcare professionals who have an inherent scepticism or mistrust in the use of technology,” said Clayton Hamilton, who leads the eHealth and innovation portfolio of the World Health Organization’s European Region. If doctors cannot easily master new technologies, they will spend more time handling data and less time talking to patients. There is a need for involvement of all actors of the health system, in the creation of patient-outcomes oriented healthcare. This includes policymakers, companies, doctors, patients and insurance and care providers.

> *“The doctor should see his or her role as being best friend and adviser”*

Access to new digital tools should not be a way of bypassing relationships between patients and doctors, said Lorenzo Chiari, head of the interdepartmental centre for industrial research in health sciences and technologies at the University of Bologna. New technologies matter to patients, but people and relationships will still matter just as much or more, and the e-health ecosystem should cooperate in ensuring technologies are always rooted in strong scientific evidence, Chiari added.

“The doctor should see his or her role as being best friend and adviser,” added Tiik, of Finland’s Sitra. Far from replacing face-to-face time, new digital tools should improve the doctor-patient interface, argues Blanca Usoz Oyarzábal, a Spanish doctor, by “freeing up more time for doctor-patient interaction.”

Technology may change, but one thing should never vary: Doctors need to maintain the mentality that their role is not merely to treat illness – “but to treat human beings,” said Christian Grasu, state secretary for health in Romania and medical doctor. “There is an art to medicine: sympathy may outweigh the knife. (As technology advances) we have to think twice: Are we improving the partnership with the patient?”

SCIENCE|BUSINESS®

Healthy measures

An initiative to improve Europe's health systems – through smarter use of data

Health systems across the European Union are big, complex organisations – hard to run, and often hard to navigate as a patient. Better data would help: Better data about what works and doesn't work in treating specific kinds of patients. Better data on which medicines and equipment, what kind of doctor and nurse training, what type of hospital and administration. In short, we need better data on what produces the best possible outcomes for patients.

The EU member-states are stepping up efforts to manage data more effectively – and the Science|Business Healthy Measures initiative aims to help spread knowledge and expertise on the subject around the EU. Founded by media organisation Science|Business, Healthy Measures with its partners organises at least four events a year around the EU, and publishes news and special reports, on this important development.

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