

From Spectators to Change Agents: Empowering European Citizens as Drivers of e-Health Innovation

Pēteris Zilgalvis*

peteris.zilgalvis@ec.europa.eu

Head of the eHealth and Wellbeing Unit
European Commission

Sven Jungmann

sven.jungmann@oxfordalumni.org

Clinical Resident
HELIOS Klinikum Emil von Behring



INTRODUCTION

What is “e-health”? Experts disagree on the exact definition of the term, which can be interpreted in many different ways. Indeed, the term might be a gross oversimplification. One possible solution to this conceptual problem is to break down e-health into sub-components based on the healthcare problems that it intends to solve: administration, clinical decisionmaking, access to health services, patient autonomy, interdisciplinary information exchange and workflows, scientific research, patient safety, and so on.

The European Commission’s *eHealth Action Plan 2012–2020* provides another useful benchmark. It defines e-health as follows: “The use of ICT in health products, services and processes combined with organisational change in healthcare systems and new skills, in order to improve health of citizens, efficiency and productivity in healthcare delivery, and the

economic and social value of health. e-Health covers the interaction between patients and health-service providers, institution-to-institution transmission of data, or peer-to-peer communication between patients and/or health professionals.”¹

This definition rightly puts citizens at the centre of health services. e-Health, then, seeks to facilitate the generation, provision, evaluation, and communication of information for the benefit of citizens. This relies on an environment of trust whereby citizens disclose personal information to trusted entities (such as healthcare providers) and in return receive better and more personalised care.

¹ Commission of the European Communities, “eHealth Action Plan 2012–2020: Innovative Healthcare for the 21st Century”, 6 December 2012, http://ec.europa.eu/health/ehealth/docs/com_2012_736_en.pdf.



European Union
European Social Fund



Investing
in your future

This publication is funded by the European Social Fund
and the Estonian Government

This paper provides concrete policy recommendations that are applicable to the diversity of applications—and their various users—that fall under the very broad concept of e-health. It is important to note that the users, payers, and beneficiaries of a certain application can be entirely different entities.² An example of this reality is proxy use, in which family members or carers rely on information and communications technologies (ICT) to help dependent persons.

The authors invite policymakers and health practitioners to reflect on ways in which the recommendations of this paper could be applied to achieve their respective purposes. The paper will argue that while e-health efforts generally focus on technological innovation, the problems they address also have a strong human component that needs to be strengthened at both the individual and the systems levels.

BACKGROUND

In 2004, the European Union (EU) adopted its first eHealth Action Plan with the aim of fostering widespread adoption of e-health for the benefit of European citizens and society. The strategic goal was, and continues to be, the advancement of equitable citizen-centred health systems that respect cultural and vernacular traditions across EU Member States.³

The development of e-health has the potential to improve the quality of healthcare services while reducing access barriers and costs. It therefore raises hopes that it will help Europe successfully tackle the challenges of providing health services to an aging population in spite of rising financial constraints. It is also expected to support basic European values of solidarity, universality, and equity, and facilitate the freedom of movement of European citizens for work, study, or tourism. Simultaneously, e-health can enable value-added economic growth in the innovation economy and supply scientific research and public health services with high-quality health data. Box 1 illustrates how e-health solutions can improve healthcare provision by using Electronic Health Records (EHR) as an example.

Box 1:

Case in Point for the e-Health Action Plan: How Electronic Health Records Simultaneously Address Multiple Challenges.

When clinicians first prescribe medications, Electronic Health Records (EHR) can automatically warn of drug interactions, allergies, and incorrect dosages.⁴ This enhances safety and frees up the mental bandwidth of doctors for other tasks, enhancing the job satisfaction of a highly skilled workforce. Access to health records by different specialists improves diagnostic workups and reduces the need for redundant tests.⁵ This is crucial: redundancies and inefficiencies can account for a large portion of total healthcare costs. Potentially, EHR can support Europe's Freedom of Movement Principle by facilitating the care continuum to all citizens irrespective of their locations. EHRs could also become an important tool for disease surveillance, policy evaluation, and medical research, with the potential to reduce mortality and morbidity significantly. If combined with a service such as NHS Choices, a free web service that provides comprehensive health information to help put citizens in control of their healthcare (see www.nhs.uk), EHRs can empower citizens by providing them with individualised health information on demand.

The idea of building EHRs on a continent-wide scale also creates concerns. Similar to other ICT aspects,⁶ this process is prone to massive cost and schedule overruns; a recently abandoned British EHR venture that lost £10bn of investments is an unfortunate example.⁷ EHRs are fraught with challenges such as data security and obstacles to interoperability. Experts stress the importance of stakeholder buy-in for the development and sustainability of community-wide data-sharing.⁸ Front-end user resistance is often seen as a barrier, but may reflect sensible concerns that can guide meaningful improvements. For example, replacing paper charts with computers can impair the patient-doctor interaction.⁹ EHR systems designers must take these concerns into account.

2 Vishal Gulati, "MedCity x TechCity: London's Winning Duo for Digital Health Start-ups?" Panel discussion at the Oxbridge Biotech Roundtable London Chapter, St Bartholomew's Hospital for the Robin Brook Centre, 30 July 2014.
3 Ibid.

4 Richard Hillestad et al., "Can Electronic Medical Record Systems Transform Health Care? Potential Health Benefits, Savings, and Costs," *Health Affairs (Project Hope)*, Vol. 24, No. 5 (October 2005), pp. 1103–1117.
5 Julia Adler-Milstein and David W. Bates, "Paperless Healthcare: Progress and Challenges of an IT-Enabled Healthcare System," *Business Horizons*, Special Issue on Healthcare and the Life Sciences in Transition, Vol. 53, No. 2 (March 2010), pp. 119–130.
6 Alexander Budzier and Bent Flyvbjerg, *Double Whammy—How ICT Projects Are Fooled by Randomness and Screwed by Political Intent*, SSRN Scholarly Paper (Rochester, N.Y.: Social Science Research Network, 1 August 2011), <http://papers.ssrn.com/abstract=2238057>.
7 Rajeev Syal, "Abandoned NHS IT System Has Cost £10bn so Far," *The Guardian*, 25 March 2015.
8 Grossman, Kushner, and November, "Creating Sustainable Local Health Information Exchanges"; Kathryn Kushner and Sarath Malepati, "RHIOs and the Value Proposition. Value Is in the Eye of the Beholder," *Journal of American Health Information Management Association*, Vol. 78, No. 3 (March 2007), pp. 24–29; quiz, pp. 31–32.
9 Pantelis Angelidis, "The eHealth Manifesto: A Call to Action for a Healthier Europe," Digital Agenda for Europe.

Building on past achievements, a second plan, the *eHealth Action Plan 2012–2020*, was adopted in 2012 and endorsed by the European Parliament in 2014. Among other issues, the Plan recognised the need for more patient-centric care, citizen empowerment, and organisational changes. Since 2004, Europe has made impressive advances in e-health. Examples include regional projects such as Klamydia.se in Sweden and the HELIOS teleradiology pilot project in Germany as well as cross-national ventures promoting the interoperability of systems across Europe, such as the Regional Telemedicine Forum’s good practice guides, ANTILOPE, and the eSOS interoperability pilot.

Further efforts are needed, however, to achieve and maintain European excellence in e-health innovation. Europe’s e-health potential has not yet been fully realised. The few success stories and promising pilot projects are the bright spots; but there are also a variety of failed initiatives that have sunk major investments.¹⁰ At a time when interoperability is becoming crucial, many European healthcare providers still operate within siloed systems, especially in large countries such as France and Germany. More generally, low ICT adoption rates are idiosyncratic to the healthcare industry.¹¹ Much greater progress has been achieved in other sectors of the economy and non-market spheres. This is problematic because positive performance requires high levels of end-user participation both in the implementation and operational phases.

Several studies have identified key barriers to the strategic implementation of e-health, including unclear legal frameworks and lack of reimbursement schemes,¹² misaligned incentives,¹³ and traditional business environments that do not work well for e-health entrepreneurs.¹⁴ While promising solutions have been proposed or are being implemented, resolving technical challenges alone will not lead to successful implementation of e-health innovations. Any attempts to introduce new

technologies are unlikely to succeed if the human implications are not properly addressed. Diffusion occurs within a social system;¹⁵ its success therefore relies on the inclusion of empowered front-end users (patients, nurses, doctors, and pharmacists) throughout the entire lifecycle of an e-health project. Empowerment requires that users possess the skills, understanding, and political voice to help shape innovations in the ways that best suit their needs.

“We live in a society exquisitely dependent on science and technology, in which hardly anyone knows anything about science and technology.”

Carl Sagan

Yet despite abundant warnings about the perils of inadequate front-end user inclusion, and experiences of project failure due to its absence, actionable recommendations remain scarce. This paper aims to fill this gap in understanding by offering strategies to shape a European culture of front-end users as drivers of e-health innovation. This culture of inclusive innovation goes beyond the recognition that a lack of stakeholder buy-in is a barrier to the success of e-health innovations.¹⁶ It also enables front-end users to become a valuable source of information and to act as co-creators and citizen-innovators.

Above all, an inclusive culture empowers citizens to contribute proactively to democratic deliberations on a vitally important social issue. Front-end users are not a barrier to surmount; rather, they are important gatekeepers who should be actively engaged. Resistance to adoption is an opportunity to guide improvements. The following recommendations are ambitious—just like the goals of the eHealth Action Plan and Horizon 2020. Europe’s political dedication and human capacities raise hopes that such high aspirations are attainable.

The Challenge

Despite a host of successful pilot projects, many e-health ventures fail to achieve sustainability and expansion. Stronger front-end user inclusion throughout the entire cycle is required. But it is often unclear how this engagement can occur.

¹⁰ The National Programme for IT in the NHS is probably among the most salient examples. It was originally estimated to cost around £6bn in 2002 but was shut down in 2011 with current cost estimates totalling around £12bn. Oliver Campion-Awwad et al., “The National Programme for IT in the NHS: A Case History,” MPhil Public Policy, University of Cambridge, February 2014.

¹¹ HIMSS Europe, *Strategic Interoperability in Germany, Spain and the UK: The Clinical and Business Imperative for Healthcare Organisations*, HIMSS Media 2014, www.intersystems.com/assets/Strategic-Interoperability-in-Germany-Spain-and-the-UK-The-Clinical-and-Business-Imperative-for-Healthcare-Organisations.pdf; Tobias Mettler and Markus Eurich, “A ‘Design-Pattern’-Based Approach for Analyzing E-Health Business Models,” *Health Policy and Technology*, Vol. 1, No. 2 (1 June 2012), pp. 77–85.

¹² European Parliament, “eHealth Action Plan 2012–2020: Innovative Healthcare for the 21st century.”

¹³ Good eHealth Team, *eHealth in Action: Good Practice in European Countries*; Jan Walker et al., “The Value of Health Care Information Exchange and Interoperability,” *Health Affairs (Project Hope) Market Watch*, Suppl Web Exclusives W5–10–W5–18 (June 2005).

¹⁴ Ray Pinto and Maria Baracsi, “Creating an Environment for Innovative Start-Ups in Healthcare,” *Health Policy and Technology*, Vol. 1, No. 4 (December 2012), pp. 187–192.

¹⁵ Everett M. Rogers, *Diffusion of Innovations*, 5th ed. (New York: Simon and Schuster, 2003).

¹⁶ K. A. Stroetmann, J. Artmann, and Veli N. Stroetmann, *eHealth Strategies Report: European Countries on Their Journey towards National eHealth Infrastructures* (Brussels: European Commission, January 2011), www.ehealth-strategies.eu/report/eHealth_Strategies_Final_Report_Web.pdf.

The Causes

A digital divide prevails in Europe. Even talented clinicians may struggle to adopt new ICT solutions. Transaction costs to implementation are unnecessarily high. Siloed structures, lack of interoperability between e-health systems, residual social norms from the pre-digital era, and doubts about the benefits of e-health are barriers to adoption whose resolution requires open discourse.

The Cures

Engaging front-end users first requires enhancing digital literacy. A culture must emerge that enables users to become proactive drivers of innovation and implementation. This culture should be solidified by an inclusive and transparent innovation ecosystem that translates skills and attitudes into constructive action. Moreover, innovations themselves can be improved to speed up their adoption.

1 Close the Digital Divide.

In order to maximise improvement from ICT innovation in health, we must develop human capacity to take advantage of new technological possibilities. With narrowing divides in access to the Internet and its increasing ubiquity in everyday life, it is apparent that the term “digital divide” signifies much more than simply access;¹⁷ it also concerns the quality of access and personal technological capabilities. Access to the Internet remains a problem, however, especially in rural areas and islands that could most benefit from the convenience of e-health.

THE CHALLENGE

“How one uses IT would seem to be far more important than simply how much one spends.”

Raymond Panko

One hundred million Europeans have never used the Internet.¹⁸ Citizens who are less educated (see Figure 1), less affluent, geographically isolated, aged, or disabled run the risk of being further excluded from digital services and progress. They are also likely to suffer disproportionately from chronic diseases and ill health while generally having less access to health services. While they stand to gain the most from new e-health services, they might benefit from such services the least, if they

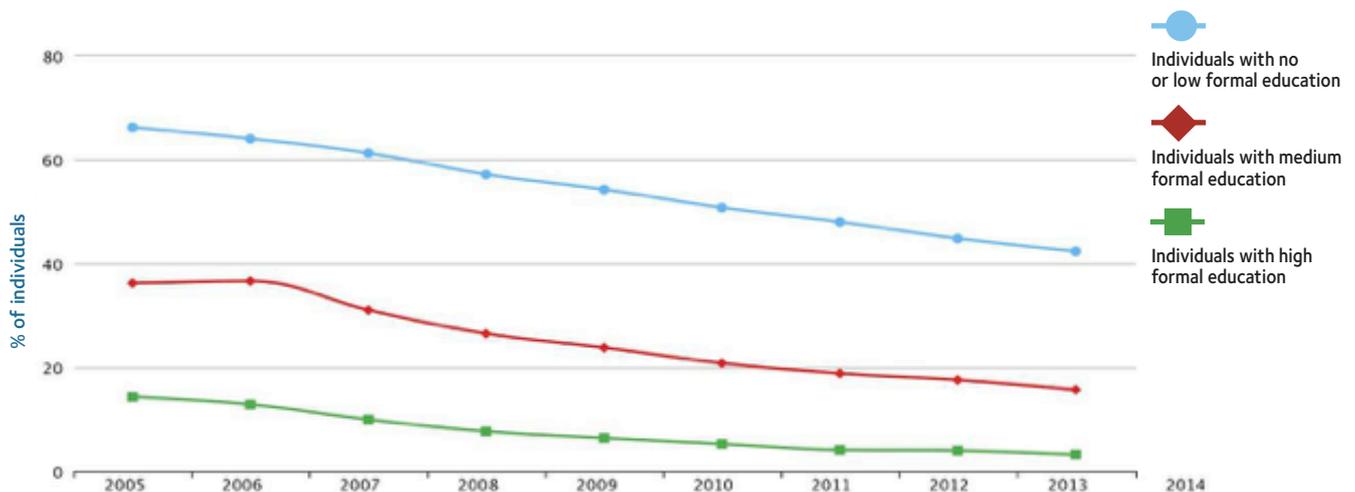
SIX RECOMMENDATIONS

Many of these recommendations are interconnected and mutually supportive. They target different levels of decision-making ranging from the top-level policy perspective to all levels of hospital management. This reflects the belief that leaders must adopt a comprehensive, holistic view of e-health issues and must cooperate across sectors.

¹⁷ Kim Andreasson, “Redefining the Digital Divide,” *The Economist Insights*, The Economist Intelligence Unit Limited (London, 2013).

¹⁸ Commission of the European Communities, “Digital Agenda Targets Progress Report,” 28 May 2014.

Figure 1: Individuals who have never used the Internet (by education level).



Source: Eurostat

do not have access or the digital literacy to use the services adequately. This could aggravate the digital divide within European societies.

Merely improving physical access is not enough because other barriers also exist. For example, Internet users find themselves flooded with health information of questionable quality. This flood of data complicates the separation of trustworthy and dependable information from unreliable—or even dangerous—information. For ICT implementation to succeed, citizens need to understand the workings and the risks of e-health technologies.¹⁹ In short, infrastructure investment is not sufficient; we must also increase digital and information literacy.

E-HEALTH LITERACY AND CITIZEN EMPOWERMENT

Some countries, such as Estonia, have taken important steps to promote public understanding of ICT through schooling. But this does not necessarily cover e-health literacy sufficiently. The literacy gap requires special attention, primarily because many tasks will be delegated from healthcare professionals to non-professionals. In some cases, expert supervision will typically be provided remotely, increasing the burden and responsibility for both patients and caregivers.²⁰ There is a need for increased literacy regarding both health generally and its delivery by digital means specifically. Citizens must be adequately empowered to benefit from this enhanced engagement and gain autonomy—not dependency—through the use of ICT.

Digital literacy also means that citizens need to understand what happens with their data. e-Health services produce, collect, analyse, store, and transfer sensitive personal data that, if publicly disseminated, could harm an individual's employability or standing in society (and those of the individual's children, if the information concerns genetic conditions). As online devices are increasingly used to generate and store medical data, citizens need to understand their rights regarding data ownership and data protection.²¹ Knowledge does not automatically translate into attitudes

and practices, but a more profound understanding will help citizens to protect their shared data and contribute to the public discourse on e-health. Users, however, should not bear the full responsibility for protecting themselves against unscrupulous business practices or unsafe technologies. The state is also responsible for ensuring that privacy choices are clearly stated and robust security frameworks are in place when data is shared or moved to the cloud (i.e., remote data storage accessible via the Internet). By requiring clear statements of privacy choices, the state will create conditions for a better informed citizenry. Discussions around tobacco warnings or food labelling highlight the difficulties of designing meaningful declaratory requirements. These difficulties make timely updated legal requirements for cloud service security frameworks (“privacy by design”) even more important.

Maintaining equity in healthcare requires efforts to promote digital and information literacy that encompass all sub-populations. Wide Internet usage disparities persist between EU Member States (see Figure 2). These disparities partially explain Europe's heterogeneous development and diffusion rates of e-health innovations. The fourth and sixth pillars of the Digital Agenda for Europe go a long way toward creating a more empowering environment.

LEVERS

In addition to the measures currently taken under the umbrella of the Digital Agenda, more can be done to further educate the public about e-health. Although most governments have not exhausted the potential of their own levers (e.g., employment agencies could host e-health career events), they should simultaneously strive to increase support from other public and private players. Examples of such players include the media, health insurers, and healthcare providers.

The media is highly useful in increasing public knowledge about current e-health possibilities and practices. Information should be tailored to the needs of different audiences. For example, young individuals might be more interested in learning about tools that promote a sporting lifestyle or career opportunities in e-health. Conversely, elderly people with nursing needs might favour information on innovations that increase their autonomy, safety, and mobility. Accordingly, media campaigns should rely on a sensible mix of paid, owned, and earned channels.²²

The role of payers as levers merits further investigation. Many health insurance companies offer subsidies for preventative measures to their members, such as fitness studio memberships. It is in the payers' interest to promote e-health technologies that reduce their costs. For example,

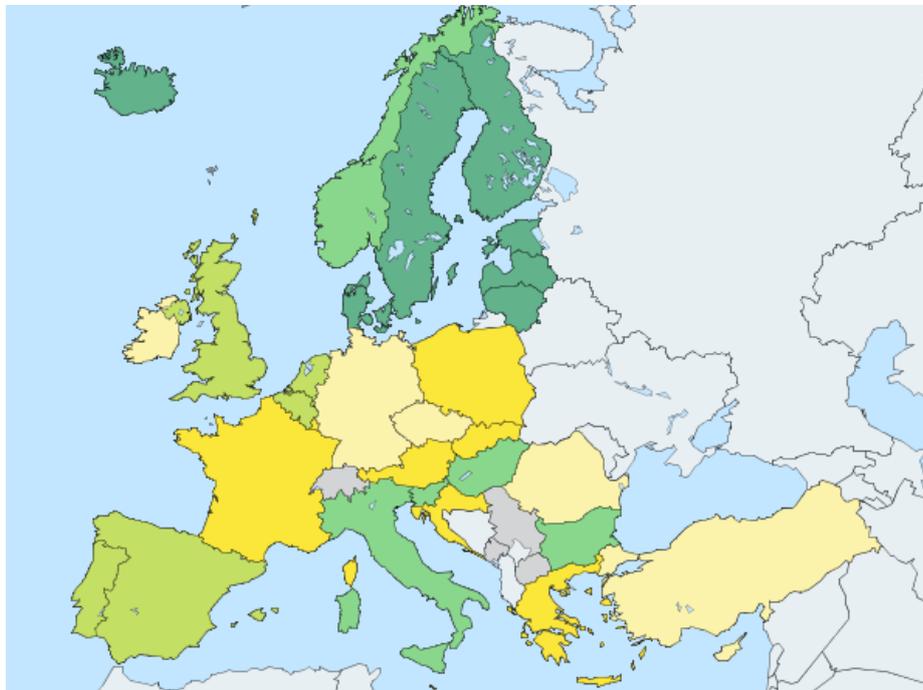
19 K. Keshavjee et al., “Best Practices in EMR Implementation: A Systematic Review,” *AMIA Annual Symposium Proceedings* (2006), p. 982; D. A. Ludwick and John Doucette, “Adopting Electronic Medical Records in Primary Care: Lessons Learned from Health Information Systems Implementation Experience in Seven Countries,” *International Journal of Medical Informatics*, Vol. 78, No. 1 (January 2009), pp. 22–31; Amy K. Yarbrough and Todd B. Smith, “Technology Acceptance among Physicians: A New Take on TAM,” *Medical Care Research and Review: MCRR*, Vol. 64, No. 6 (December 2007), pp. 650–672.

20 Angelo Rossi Mori et al., “Holistic Health: Predicting Our Data Future (from Inter-Operability among Systems to Co-Operability among People),” *International Journal of Medical Informatics*, Vol. 82, No. 4 (April 2013), pp. 14–28.

21 Julia Adler-Milstein and Robert S. Huckman, “The Impact of Electronic Health Record Use on Physician Productivity,” *American Journal of Managed Care*, Vol. 19, No. 10 (25 November 2013).

22 “Word of mouth” is an example of an earned channel.

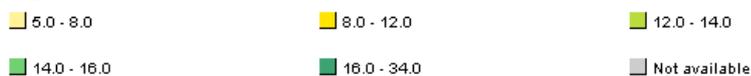
Figure 2: Individual levels of Internet skills.



% of the total number of individuals aged 16 to 74 - 2013

Individuals who have carried out 5 or 6 Internet related activities

Legend



Minimum value:5.0 Maximum value:34.0

Source: Eurostat

Hyperlink to the map:

<http://ec.europa.eu/eurostat/tgm/mapToolClosed.do?tab=map&init=1&plugin=1&language=en&pcode=tsdsc470&toolbox=legend>

Short Description: Level of internet skills are measured using a self-assessment approach, where the respondent indicates whether he/she has carried out specific tasks related to internet use, without these skills being assessed, tested or actually observed.

Six internet-related items were used to group the respondents into levels of internet skills in 2005, 2006, 2007 and 2011: use a search engine to find information; send an e-mail with attached files; post messages to chatrooms, newsgroups or any online discussion forum; use the internet to make telephone calls; use peer-to-peer file sharing for exchanging movies, music etc.; create a web page.

Low level of basic internet skills: Individuals who have carried out 1 or 2 of the 6 internet-related items.

Medium level of basic internet skills: Individuals who have carried out 3 or 4 of the 6 internet-related items.

High level of basic internet skills: Individuals who have carried out 5 or 6 of the 6 internet-related items.

Oscar Health, a young New York-based insurance company, drives user-friendly e-health innovation and promotes e-health literacy among its customers.²³ When engaging

payers, however, caveats are attached wherever conflicts of interest arise that may harm equity in access to health insurance.

²³ Julie Creswell, "Start-Up Health Insurer Finds Foothold in New York," *New York Times*, 28 March 2014.

Healthcare professionals also play a pivotal role in the e-health education of their patients. Those who cultivate a holistic approach to healthcare must adopt a view that sees individuals not just in their social, but also in their technological context. Healthcare professionals should regard e-health solutions as complementary to other healthcare interventions, such as medical and surgical therapies or lifestyle recommendations. Healthcare professionals can inform their patients about the practicalities of e-health solutions based on other patients' experiences.

LIMITATIONS

Notwithstanding the enormous beneficial potential of e-health, citizens should be informed about its relevant limitations and risks to help them understand the full implications of their decisions and manage their expectations. Because not everybody is willing or able to live digitally, it is necessary to avoid the prospect of a “digital tyranny” that systematically disadvantages those who do not partake in digital life. More research is required on mechanisms to accommodate the needs of subpopulations with special needs, such as those with mental disorders. Research is also needed on the possible harm to health, learning processes, and capabilities that the increasing use of digital devices at ever-younger ages may produce. While this study is positive about the digital transformation that our societies are undergoing, this does not mean that every use of digital technologies will turn out to be beneficial. We must continue to monitor the health, societal, and educational impacts of the move toward a “digital life.”

ICT is not a panacea for every health challenge, but rather a powerful tool to advance patient-centric services. In addition to further improving ICT infrastructures and digital literacy, provisions must be made to provide equitable access to health services, regardless of individual capacity or desire to use e-health technologies.

2 Enhance ICT Training for Health Professionals.

EXTENDED REQUIREMENTS

Healthcare providers are both front-end users and co-shapers of complex ICT systems. ICT innovation, adoption, and reinvention succeed through them. As one study affirms: “The most important part of e-health investment that needs expanding is the e-health skills and knowledge of healthcare staff and ICT suppliers' staff. An expanded capability is essential to achieve more success in boosting e-health

investment.”²⁴ New technology can facilitate or even stimulate the redesign of existing services.²⁵ Because of the paucity of links between designers and front-end users, designers cannot be fully aware of how their innovations interact with clinical realities.²⁶ But even with the best information, unexpected side effects—good and bad—are always a possibility when new technologies are adopted.²⁷

To narrow the various gaps between design and reality in e-health, it is necessary to shape a critical mass of “hybrids,” i.e., individuals who share the roles of both developer and front-end user. Besides facilitating the redesign of workflows and highlighting problematic issues, hybrids can also provide training for others.²⁸ This can reduce costly and labour-intensive staff training when implementing new technologies. Reports suggest that staff perceive gaps in awareness as a barrier to deriving the maximum utility from e-health.²⁹ ICT capacities need to be built at tertiary education and vocational training levels to reduce the burden on healthcare facilities.

Additionally, in order to educate patients about e-health, it is necessary for healthcare providers to possess a deeper understanding of e-health than the average layperson. Ultimately, doctors must come to understand digital technologies as part of their core toolkit for diagnosis, treatment, prevention, communication, research, and service innovation. This entails a radical redefinition of the medical profession. While the profound need for ICT skills in the European workforce has been officially recognised since 2007,³⁰ European medical school curricula do not typically reflect this need. Doctors mostly rely on personal experience and public media reports about ICT to guide their adoption decisions and patient consultations.

- 24 Alexander Dobrev et al., “Sources of Financing and Policy Recommendations to Member States and the European Commission on Boosting eHealth Investment,” December 2008, http://www.financing-ehealth.eu/downloads/documents/FeH_D5_3_final_study_report.pdf.
- 25 L. Cancian et al., “Policy Recommendations for Deployment of Telemedicine Services, Deliverable D3.6, Regional Telemedicine Forum,” Interreg IVC (Lille, 20 July 2012).
- 26 Robin Williams and David Edge, “The Social Shaping of Technology,” *Research Policy*, Vol. 25, No. 6 (September 1996), pp. 865–899.
- 27 Donald A. MacKenzie and Judy Wajcman, eds., *The Social Shaping of Technology*, 2nd ed. (Philadelphia, Pa.: Open University Press, 1999).
- 28 Richard Heeks, “Health Information Systems: Failure, Success and Improvisation,” *International Journal of Medical Informatics*, Vol. 75, No. 2 (February 2006), pp. 125–137.
- 29 Good eHealth Team, *eHealth in Action: Good Practice in European Countries*.
- 30 Commission of the European Communities, “E-Skills for the 21st Century: Fostering Competitiveness, Growth and Jobs,” 7 September 2007, http://ec.europa.eu/health/ehealth/docs/com_2012_736_en.pdf.

PROMOTE GREATER ICT SKILLS

Thus, the integration of interdisciplinary e-health training at all levels in the academic curricula of health and care education is necessary.³¹ This entails training on data security and data protection, especially for staff who are directly engaged in the use of ICT for patient care.³² Ultimately, e-health should enter core curricula and qualifying national board examinations. The White Paper of the International Medical Informatics Association on Education in Biomedical and Health Informatics already provides comprehensive recommendations on what training needs should be met.³³ Observers may also be interested in the forthcoming eHealth Stakeholder Group Report on eSkills and Health Care Workforce, a study led by Paul de Raeye.

Resistance to compulsory teaching can be expected from both students and faculty management. Medical curricula are already demanding and costly to students and society. With six years of minimum study required in most countries, there is little scope for increasing workloads; it is important not to integrate into curricula every single new idea that comes into fashion. ICT is too important and too central, however, to be neglected in the education of health professionals. A tiered system will help strike a balance between needs and capacities. While baseline technological skillsets should become compulsory, complementary optional modules could cover additional topics above the minimum threshold.

Moreover, digital innovations in education delivery might enhance the feasibility of additional e-health training. Universities with insufficient teaching capacities could rely on massive open online courses (MOOCs).³⁴ We should be careful, however, to avoid the use of online distance learning as an excuse to cut essential on-site courses. Digital methods of instruction should increase student access to courses, overcoming restrictions imposed by geography or the limitations of disciplines taught in a specific locality. Courses also should be available outside universities in order

to reach senior healthcare professionals and those working in remote areas.

Demand for e-health courses can be incentivised through certification for continuous medical education, or by requiring certifications for e-health service providers. For example, the Scottish Qualifications Authority now offers a Professional Development Award for those working in tele-healthcare. Such certification can turn e-health qualifications into a competitive advantage on the labour market. Additionally, “Awards of Excellence” could be granted to institutions that are making a meaningful contribution to the advancement of ICT literacy among health professionals through formal teaching or the creation of learning materials.

CORRECT DIFFERENTIAL RATES OF ADOPTION

Skills acquisition will happen at different rates across sub-populations. Older healthcare practitioners often require more time to become comfortable with ICT; this can hinder innovation diffusion at institutions with strong hierarchies where senior staff are unwilling to support changes. Some individuals might decide to retire early owing to the high transaction costs of adjusting to a rapidly changing digital working environment. More digitally literate staff might be recruited, leaving less adapted individuals behind.

Simply waiting for a generational change in leadership positions is neither ethical nor feasible. It is not ethical because everybody should be empowered as much as possible to reap the benefits of ICT innovations; older healthcare workers with considerable expertise should not be disregarded, nor should citizens’ access to improved healthcare services be unnecessarily delayed. It is not feasible because innovations can be expected to advance exponentially.³⁵ Thus, front-end users are likely to face widening skills gaps.

A buddy system, in which junior staff are paired with senior staff to guide them in the use of ICT, may help here. Capacity inequalities are not confined to age; a gender gap disfavouring women may also exist. At the same time, we should not resort to stereotypes: many older people and women are digitally savvy, while being young and male is not a guarantee of digital literacy generally or of e-health literacy specifically. We hope that new research will elucidate where digital skills are lacking the most—and why.

31 Cancian et al., “Policy Recommendations for Deployment of Telemedicine Services, Deliverable D3.6, Regional Telemedicine Forum”; interview with Norbert Graf; Christoph F.-J. Goetz and Andreas Grode, *Thesenpapier zur Gesundheits telematik. Ziele, Strategien und Impulse wichtiger Stakeholder für eine funktionelle Gesundheitstelematik in Deutschland* (Berlin: TeleTrusT—Bundesverband IT-Sicherheit e.V., 2013).

32 José Luis Fernández-Alemán et al., “Security and Privacy in Electronic Health Records: A Systematic Literature Review,” *Journal of Biomedical Informatics*, Vol. 46, No. 3 (June 2013), pp. 541–562.

33 John Mantas et al., “Recommendations of the International Medical Informatics Association (IMIA) on Education in Biomedical and Health Informatics (First Revision),” *Methods of Information in Medicine*, Vol. 49, No. 2 (7 January 2010), pp. 105–120.

34 Rice University offers a course on “Fundamentals in Computing” and “Algorithmic Thinking” on coursera.org, and Ryzac Inc. reports 24 million registered users of its e-learning service codecademy.com. Other notable initiatives are edX and Khan Academy. Similar courses could be offered by European entities in different languages and within a European context. There is still a lack of evidence proving that the MOOC method of instruction is successful in the area of e-health, however.

35 John Naughton, *From Gutenberg to Zuckerberg: What You Really Need to Know About the Internet* (London: Quercus, 2012).

SUPPORT HIGHER ASPIRATIONS IN E-HEALTH

Europe should accommodate the needs of citizens who want to build their careers around e-health. This requires increasing the availability of training. Recent “Translational Medical Research” programmes, which aim to bridge gaps between clinicians and basic researchers, can inspire citizens to seek more training.

The Karolinska Institute (with its interdisciplinary Master’s programme in Health Informatics) and University College London’s Centre for Health Informatics & Multiprofessional Education (CHIME) are championing e-health aspirations. Similarly, the Royal College of Surgeons of Edinburgh provides a Diploma in Remote and Offshore Medicine, which covers telemedicine. There remains scope in the education market for more e-health courses with different focuses and modes of delivery to satisfy different needs. There is a lack of institutions that research and teach the peculiarities of the e-health business—for example, the question of how to establish effective business models in e-health or how to design revenue streams.

3 Leverage the Factors of Innovation Diffusion.

Human capacity must coincide with a culture that is supportive of digital innovation.³⁶ The following recommendations address different elements affecting the speed with which innovations spread, the intrinsic characteristics of a novel idea, and heuristics on the external factors that facilitate adoption. Only a comprehensive strategy that acts on all three levers—skills, adoptability, and environment—will help Europe unlock its full potential in a sector that is “large, ubiquitous and pervasive, affecting every citizen of all ages, and employing some 10% of the national workforce in most OECD countries.”³⁷ Designers, policymakers, and implementers must understand the five factors, as perceived by individuals, that explain why certain innovations spread quickly: relative advantage, compatibility, complexity, trialability, and observability.³⁸ This classification closely matches the European context of e-health innovation diffusion.

MAXIMISE THE RELATIVE ADVANTAGE OF E-HEALTH SOLUTIONS

According to Everett Rogers, “relative advantage is the degree to which an innovation is perceived as better than the idea it supersedes.”³⁹ The notion of individual perception rather than objective advantage is key to this definition. Digital innovations often instigate changes in workflows, altering existing patterns and structures. This situation yields both benefits and new challenges to different actors. Ideally, all involved should reap benefits that cover their costs in value.⁴⁰ In other words, all participants will have to make sacrifices (e.g., making investments, changing habits, and learning new skills). These sacrifices must be worth making. The diverse impacts on different actors (see Table 1) are not immediately intelligible or measurable, however, and the player in question might not be the actual beneficiary, producing disincentives against participation.

36 Chon Abraham, Eitaro Nishihara, and Miki Akiyama, “Transforming Healthcare with Information Technology in Japan: A Review of Policy, People, and Progress,” *International Journal of Medical Informatics*, Vol. 80, No. 3 (March 2011), pp. 157–170.

37 Michael Rigby, Elettra Ronchi, and Susan Graham, “Evidence for Building a Smarter Health and Wellness Future—Key Messages and Collected Visions from a Joint OECD and NSF Workshop,” *International Journal of Medical Informatics*, Vol. 82, No. 4 (April 2013), pp. 209–219.

38 Rogers, *Diffusion of Innovations*.

39 *Ibid.*

40 Alexander Dobrev et al., “Interoperable eHealth Is Worth It—Securing Benefits from Electronic Health Records and ePrescribing” (Brussels: European Commission, February 2010), <http://ec.europa.eu/digital-agenda/en/news/interoperable-ehealth-worth-it-securing-benefits-electronic-health-records-and-eprescribing-0>.

Table 1: Examples of perceived advantages and disadvantages of interconnected digital health records by actors.

	Advantages	Disadvantages
Patients	<ul style="list-style-type: none"> ↑ safety ↑ mobility ↓ redundant examinations ↑ responsibility for own health ↑ knowledge about health and diseases • better basis for shared decision-making • improved coordination in care 	<ul style="list-style-type: none"> ↑ privacy risks
Healthcare workers	<ul style="list-style-type: none"> • improved workflows • time savings • better outcomes • more services or wider regional coverage possible 	<ul style="list-style-type: none"> ↓ revenues due to fewer examinations • patients are less dependent on individual service providers because they can carry their data with them ↑ micro-management ↓ therapeutic autonomy
Hospital managers	<ul style="list-style-type: none"> • informed decisionmaking ↓ cost due to increased efficiency ↑ revenue (improved billing) 	<ul style="list-style-type: none"> • disclosing strategic information ↑ cost (investments)
Researchers	<ul style="list-style-type: none"> ↑ data for research 	<ul style="list-style-type: none"> ↓ data ownership
Payers	<ul style="list-style-type: none"> ↑ scrutiny and control ↓ cost (e.g., healthier clients) 	<ul style="list-style-type: none"> ↑ cost (from better cost capture by service providers and direct investment costs)

It is therefore most promising to focus on innovations that are subject to little or no controversy about their relative advantage, followed by careful and incremental additions. As one study points out, engagement of front-end users (including patients) provides a helpful context in which to set priorities, requirements, and benefits. Health information exchange systems, for example, highlight the opportunity to focus on interoperability as a prime driver of benefits, which “makes life easier for users and provides gains that rely on access to information regardless of place and time, and from reusing information for multiple purposes.”⁴¹

In fact, well-designed and user-friendly systems can experience strong physician support if organisations shape a favourable environment and the systems improve communication between healthcare workers and patients.⁴² Especially in situations where time is scarce, tolerance for delays—even of several

minutes—is low.⁴³ Physician resistance is a frequent barrier to adoption.⁴⁴ In one institution, a physician revolt caused a multimillion-dollar digital health programme to fail because it was deemed too time consuming.⁴⁵ Conversely, clinicians can also be the key driving force of innovation adoption in hospitals.⁴⁶ To reduce the risk of implementing systems that are prone to failure or that create friction in workflows, functionalities should focus, initially, on solving problem in a piecemeal fashion.

The benefits of e-health are a matter of perception. Some individuals will value the long-term benefits of e-health competency more than its immediate financial returns because competitiveness in the labour market and credibility among peers will increasingly depend on individuals’ ability to interface with computers. Those who are at the forefront of current developments stand high chances of reaping the most benefits from them.

Ultimately, as in other sectors, ICT expenditures should be seen as an investment designed to improve multiple problems, such as coordination in care, which might directly benefit

41 Joy M. Grossman, Kathryn L. Kushner, and Elizabeth A. November, “Creating Sustainable Local Health Information Exchanges: Can Barriers to Stakeholder Participation Be Overcome?” *Research Brief*, No. 2 (February 2008), pp. 1–12.

42 Patrick Y. K. Chau and Paul J. Hu, “Examining a Model of Information Technology Acceptance by Individual Professionals: An Exploratory Study,” *Journal of Management Information Systems*, Vol. 18, No. 4 (March 2002), pp. 191–229; Rai-Fu Chen and Ju-Ling Hsiao, “An Investigation on Physicians’ Acceptance of Hospital Information Systems: A Case Study,” *International Journal of Medical Informatics*, Vol. 81, No. 12 (December 2012), pp. 810–820; Douglas S. Wakefield et al., “Development of a Measure of Clinical Information Systems Expectations and Experiences,” *Medical Care*, Vol. 45, No. 9 (September 2007), pp. 884–890.

43 Interview with Claus Duedal Pedersen.

44 Ashish K. Jha et al., “Use of Electronic Health Records in U.S. Hospitals,” *New England Journal of Medicine*, Vol. 360, No. 16 (16 April 2009), pp. 1628–1638.

45 M. L. Langberg, “Challenges to Implementing CPOE,” *Modern Physician*, Vol. 7, No. 2 (2003), pp. 21–22.

46 Interview with Claus Duedal Pedersen.

patients and reduce costs to payers and hospitals.⁴⁷ We must accept that many benefits will accrue to society as a whole and not necessarily to individual payers. In the case of Odense University Hospital in Denmark, for example, a programme to improve care for diabetes via telemedicine is maintained although it incurs negative returns; the benefits to patients are considered too significant to justify abandoning the programme for financial reasons.⁴⁸ Over time, with accumulating evidence of long-term effectiveness, new ICT projects can become established standards of practice for which payment and subsidy schemes can be adapted to ensure sustainability and a fair distribution of the financial burden.

ENHANCE COMPATIBILITY

The term “compatibility” denotes “the degree to which an innovation is perceived as being consistent with the existing values, past experiences, and needs of potential adopters.”⁴⁹ The health sector is often based on strong traditions and shared values, some dating back to antiquity. These encompass the strong social standing of health professionals, a focus on human interaction, ample factual knowledge, expertise as a privilege of the professional elite, and a high degree of decisional autonomy.

“We in medicine continue to exist in a system created in the Master Builder era—a system in which a lone Master Physician with a prescription pad, an operating room, and a few people to follow his lead plans and executes the entirety of care for a patient, from diagnosis through treatment.”⁵⁰

Atul Gawande

ICT is eroding the traditional image of a “Master Physician.” It is doing so by reducing information asymmetries between citizens and doctors as well as by making information accessible to everyone at minimal cost. In addition, machines dwarf any doctor’s ability to collect, memorise, and process medical information. Current values and norms are challenged to such a degree that some observers refer to our times as the Second Machine Age.⁵¹ According to IBM, it would take a human doctor 160 hours of reading per week to stay up to date with new literature.⁵² Machines can improve personalised diagnosis and treatment by predigesting the vast amount of data needed to guide humans. If, however, such technologies

are perceived to undermine social standing or professional autonomy, front-end user resistance may arise.⁵³

Some tasks are easier to delegate to machines than others. Depending on their traditions and values, some specialties and institutions might also be more susceptible to the adoption of digital workspaces. Radiologists, for example, already rely heavily on digital aids. While e-health solutions can be highly compatible with existing values and norms, innovations can often produce even better attunement. At times, however, systems change is needed to improve patient centricity. Technology that improves communication across departments or between hospitals and ambulatory departments will be useful only if users are willing to work closer together with other specialists and institutions. It is important here to highlight that while technology is challenging long-established roles, ongoing changes will promote—rather than reduce—the core values of the health professions. This is particularly true where digital tools reduce mortality or morbidity.⁵⁴

Finally, Rogers’ definition of compatibility also covers “consistency with past experiences,”⁵⁵ underscoring the need to implement innovations carefully and incrementally to avoid violating the trust of the front-end users as the leadership tries to promote meaningful change. Ideally, ICT tools will free front-end users to do what they do best by making administrative and monitoring tasks much less cumbersome.

47 Interview with Stephen Chick.

48 Interview with Claus Duedal Pedersen.

49 Rogers, *Diffusion of Innovations*.

50 Atul Gawande, *The Checklist Manifesto: How to Get Things Right* (New York: Picador, 2011).

51 Brynjolfsson, McAfee, and Cummings, *The Second Machine Age*; and Frances S. Mair et al., “Understanding the Implementation and Integration of E-Health Services,” *Journal of Telemedicine and Telecare*, Vol. 13, No. 1 (1 July 2007), pp. 36–37.

52 “IBM Watson Helps Fight Cancer with Evidence-Based Diagnosis and Treatment Suggestions” (New York: Memorial Sloan-Kettering Cancer Center, January 2013).

53 Albert Boonstra and Manda Broekhuis, “Barriers to the Acceptance of Electronic Medical Records by Physicians from Systematic Review to Taxonomy and Interventions,” *BMC Health Services Research*, Vol. 10 (August 2010), p. 231.

54 D. Coskun et al., “Mortality Rate, Length of Stay and Extra Cost of Sternal Surgical Site Infections Following Coronary Artery Bypass Grafting in a Private Medical Centre in Turkey,” *Journal of Hospital Infection*, Vol. 60, No. 2 (June 2005), pp. 176–179.

55 Rogers, *Diffusion of Innovations*.

REDUCE COMPLEXITY

High levels of digital literacy will improve the capacity of populations to benefit from complex innovations. Simple ideas are not only adopted faster than others, but they are also less costly and less dangerous. One study explains: “More complex systems may be a roadblock to implementation, require frequent training, and result in end-user frustration. Under the worst circumstances, complicated systems may result in delays in the patient registration and assessment that potentially could delay therapy.”⁵⁶ Hence, wherever possible, e-health innovations should be simple to design, update, understand, implement, and use.

Attaining simplicity requires training and incentivising designers to craft user-friendly devices that reduce the need for ICT specialists to a minimum.⁵⁷ We need managers to understand the importance of good front-end design if they want the people in their institutions to adopt new digital solutions.⁵⁸ Universities could help by providing more courses that teach innovators (who do not necessarily bring first-hand experience as nurses, doctors or patients) the idiosyncrasies of e-health, thus enabling them to craft solutions that will be liked by patients and their professional carers. In fact, professional front-end designers should be employed at all stages and for all elements of an e-health solution in order to maximise user experience and simplicity.⁵⁹ This can also facilitate implementation and reduce behavioural threats to data security. An easy-to-use programme with clear descriptions and help tools could help prevent people from accidentally sharing personal health data even when it is not in their interest to do so.

Simplicity also requires that regulatory frameworks become more open to innovation, improvement, and reinvention. Currently, many regulatory processes for medical equipment function well for traditional devices but do not fit the digital reality. Existing frameworks create large entry barriers for small and medium-sized enterprises (SMEs) that significantly delay innovation cycles. Clearly, safety must be assured in any medical device; but not all elements of software require the same level of scrutiny. The certification and recertification of e-health products require a differentiated approach based on risk assessment and management, in which updates for some elements are fast-tracked to reduce administrative burden. Regulatory bodies must be staffed with specialists who can advise industry players, front-end users, and academics

knowledgeable in regulatory procedures and legal compliance. Indeed, the dialogue between regulators, developers, and users must be open on all sides, not only assisting innovators in fitting their ideas into the existing frameworks but also being ready to adapt regulatory frameworks to enable innovation.

Even with ICT-savvy front-end users and simple interfaces, easy access to expert support—including guidelines, certified training, consultancy, ICT products, and certification of vendors—is necessary.⁶⁰ Some experts highlight the importance of in-house competence, as opposed to reliance on external service providers, because it helps to promote independence and to overcome conflicts of interest.⁶¹

Another level of complexity stems from difficulties in understanding the costs and benefits of e-health solutions, ranging from uncertainties of data ownership to financial issues. For example, while capital expenditures in e-health are comparatively simple to estimate (assuming an established application), operating expenditures are often unknown to consumers in advance. Hardware and software providers have an incentive to keep set-up costs low but operational costs high. Information asymmetries between front-end users and vendors concerning long-term costs are an important source of distrust of e-health providers and their commitment to maximising social value. ICT producers, however, have little incentive to promote low-maintenance products.

In addition, clarity is required on liability issues in the case of adverse outcomes following a recommendation computed by an algorithm or misreadings of vital data by a device. It is often unclear who can be held accountable in such a situation. Intellectual property rights are a further area of uncertainty: different innovations in the value chain often come from different individuals. A lack of clarity on intellectual property rights can present end users with disincentives to engage creatively and proactively in the innovation process.

Telecommunication providers are potentially well-positioned players in the e-health field. They are widely established suppliers of data transportation and storage services and usually possess competence in rapid maintenance services and expertise in data protection.

“Don’t assume that just because you got a good solution, people will use it.”⁶²

George Crooks

56 Christopher V. Fanale and Bart M. Demaerschalk, “Telestroke Network Business Model Strategies,” *Journal of Stroke and Cerebrovascular Diseases*, Vol. 21, No. 7 (October 2012), pp. 530–534.

57 Jerry Langley and Carol Beasley, *Health Information Technology for Improving Quality of Care in Primary Care Settings* (Rockville, Md.: Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services, July 2007).

58 Interview with George Crooks.

59 Ibid.

60 Dobrev et al., “Interoperable eHealth Is Worth It—Securing Benefits from Electronic Health Records and ePrescribing.”

61 Good eHealth Team, *eHealth in Action: Good Practice in European Countries*. Doctors who wish to set up telehealth solutions in Scotland receive personal support by a specialist for the first consultations; another example is England’s Tinder Foundation.

62 Interview with George Crooks.

ENSURE TRIALABILITY

Unsurprisingly, new ideas are likelier to be adopted if they can first be sampled at little risk.⁶³ Trials of all sizes are important to convince implementers at every level, from small physician practices to large multinational programmes, that they should deploy a new technology.

Most timescales for e-health projects are currently myopic, leaving projects with too little time to prove themselves useful. If a hospital purchases a better operating theatre it can rapidly calculate benefits (e.g., in terms of reduced cleaning or maintenance time or enhanced operating capabilities). The identification of benefits is not as straightforward for ICT projects. Because of their complexity, ICT systems for hospitals often come with high capital expenditures, such as investments in development, the installation of infrastructure and software, and staff training. At the same time, the systems often rely on network effects in which utility rises with the number of users. These require time to build up, however, and individuals need to adapt their working habits and organisational procedures to the new technological environment. Finally, ICT designers have to interact with users to learn what works and what does not.⁶⁴ Taken together, this means that high upfront costs are followed by long delays until positive returns are generated. Conventionally, according to the “risk paradox,” long timescales for projects increase risks because of increased uncertainty and unplanned events, but the opposite seems true for electronic health records and ePrescribing systems.⁶⁵

If funders fail to match timescales to rates of adoption and hence fail to allow sufficient time to fully grasp the benefits and shortcomings of an innovation, sustainability is in jeopardy. Some projects require funding that lasts longer than four years to keep the developed infrastructure and software alive beyond the pilot phase—an important factor in obtaining end user buy-in.⁶⁶ Stakeholders have no incentive to dedicate time and effort to a project if they anticipate its unsustainability. The transaction cost of careful workflow adaptation, contract negotiation, training, project management, and change management, are overwhelming.⁶⁷ Innovations in e-health also require significant investments of leaders’ social capital within their institution; thus, stakeholders will commit to changes only if these seem sustainable.

For this reason, at least in some cases, projects should be coupled with other sources of funding. Matched grants offer a possible tool to help fund projects where stakeholders and investors signal sufficient belief in the innovation to share the

risk; they could also make funded projects more valuable for private investors. Alternative approaches include subsidised credit schemes specific to e-health and implementation subsidies for small practices and hospitals in low-resource environments. In general, government grants could help fill the gap that venture capital investors and other traditional sources of funding cannot cover.

PROMOTE OBSERVABILITY

Rogers states: “The easier it is for individuals to see the results of an innovation, the more likely they are to adopt it.”⁶⁸ Health professionals are accustomed to relying on rigorous studies that attempt to prove efficacy, safety, and efficiency. Benefits can take the form of quality gains (e.g., reduced mortality in a programme that warns doctors against wrong dosing or important drug interactions) and efficiency gains (time and cost savings when a smartphone software reminds patients with chronic diseases to take their medications or get their next vaccination, thereby reducing hospital admissions). For a variety of reasons, however, it is not straightforward to provide solid evidence for the benefits of digital health innovations—partly because causality can be difficult to prove in complex hospital settings, partly because this area of research is still new. Indeed, uncertain return on investment is the second-most frequently cited barrier to the adoption of e-health innovations.⁶⁹

A common problem with ICT is the “productivity paradox,” famously articulated by Robert Solow as follows: “you can see the computer age everywhere but in the productivity statistics.” Indeed, various scholars challenge the assumption that a general increase in IT investments correlates with measurable benefits.⁷⁰ This complicates the mission of ICT implementers who wish to convince healthcare professionals that their e-health projects are worthwhile endeavours—especially now that the medical community challenges even its own rigorous system of evidence-based medicine.⁷¹

Moreover, e-health generates unexpected externalities that are difficult to measure.⁷² Those who lose shares in the value chain during this redistribution have decreased incentives for compliance—e.g., some radiologists might lose revenues if exams can be analysed by a machine or other specialists in remote areas at lower cost, or laboratories might see demand

63 Rogers, *Diffusion of Innovations*.

64 Ibid.

65 Dobrev et al., “Interoperable eHealth Is Worth It—Securing Benefits from Electronic Health Records and ePrescribing.”

66 Interview with Norbert Graf.

67 Adler-Milstein and Huckman, “The Impact of Electronic Health Record Use on Physician Productivity.”

68 Rogers, *Diffusion of Innovations*.

69 Adler-Milstein and Huckman, “The Impact of Electronic Health Record Use on Physician Productivity.”

70 Paul Attewell, “Information Technology and the Productivity Paradox,” in Douglas H. Harris, ed., *Organizational Linkages: Understanding the Productivity Paradox* (Washington, D.C.: National Academy Press, 1994); Erik Brynjolfsson, “The Productivity Paradox of Information Technology,” *Communication of the Association for Computing Machinery*, Vol. 36, No. 12 (December 1993) pp. 66–77; Erik Brynjolfsson and Lorin M. Hitt, “Beyond the Productivity Paradox,” *Communication of the Association for Computing Machinery*, Vol. 41, No. 8 (August 1998), pp. 49–55.

71 Ben Goldacre, *Bad Pharma: How Medicine Is Broken, and How We Can Fix It* (London: Fourth Estate, 2013).

72 Dobrev et al., “Interoperable eHealth Is Worth It—Securing Benefits from Electronic Health Records and ePrescribing.”

for their blood tests drop significantly if redundant tests can be avoided because the patient has a digital record of all her files. It is therefore essential for leaders in e-health ventures to assess the wide implications of ICT implementation and adopt a targeted communication strategy that raises awareness about its externalities, even if it is merely narrative based.⁷³ Claus Duedal Pedersen recommends that governments provide funds for what he calls “evidence-generating implementation.”⁷⁴ Generating solid evidence for the safety, efficacy, and efficiency of e-health innovations from pilot studies can rapidly generate additional costs of above €1 million and require significant expertise. The private sector has no incentive to fund such research because the knowledge generated from it is a public good attached to collective-action problems. Public funding for evidence generation will help convince others to adopt proven innovations and attract talent to an emerging field of research, thereby filling a widely recognised skills gap.

There is also the problem of time lag in observability: lack of knowledge about the actual return on investment in large e-health projects arises largely from the failure to assess the long-term impact of e-health.⁷⁵ Analytics must become an integral part of e-health innovation cycles to provide a foundation for long term evidence-based decisionmaking.⁷⁶

Leaving aside top-level impacts such as macroeconomic implications and long-term health outcomes, observability of results also includes the direct front-end user experience. A digital record of blood sugar measurements that presents itself beautifully on a mobile phone has an observable utility that is often ignored in economic calculations. Good design is just as important in e-health as it is in other digital markets.

UNDERSTAND THE SYNERGIES BETWEEN INDIVIDUAL FACTORS

The preceding analysis examined the different intrinsic characteristics of innovations that affect their rate of adoption. These are often intertwined and mutually enforcing—for example, reducing complexity can help support observability. For every project, it is important to assess which elements are naturally more likely to be adopted quickly and which ones require customisation to improve diffusion. Generally, it is best to utilise non-linear diffusion methods by focusing on easily implemented solutions

73 Research shows that high societal benefits stem from the implementation of electronic medical records. See Samuel J. Wang et al., “A Cost-Benefit Analysis of Electronic Medical Records in Primary Care,” *American Journal of Medicine*, Vol. 114, No. 5 (1 April 2003), pp. 397–403.

74 Interview with Duedal Pedersen.

75 Liette Lapointe, Muriel Mignerat, and Isabelle Vedel, “The IT Productivity Paradox in Health: A Stakeholder’s Perspective,” *International Journal of Medical Informatics*, Vol. 80, No. 2 (February 2011), pp. 102–115.

76 Interview with George Crooks.

first and, later, adding harder elements incrementally. This approach can help shape a wider e-health culture (the topic of the next section).

Bold leadership is also necessary. One should neither cease after all low-hanging fruit have been picked, nor call for endless trials as an excuse to delay implementation. The insights described above are not an excuse to avoid adopting challenging innovations; on the contrary, it is important to improve challenging innovations along the outlined characteristics to lower diffusion barriers, particularly when dealing with changes that reduce inequities and benefit vulnerable sub-populations.

4 Shape and Promote an e-Health Culture.

“It is mistaken to think of technology and society as separate spheres influencing each other: technology and society are mutually constitutive.”⁷⁷

Donald A. MacKenzie and Judy Majcman

Much will be gained if Europe succeeds in increasing digital literacy and making e-health innovations easier to adopt. But that is not all: the trifecta of e-health innovation includes not only human capacity and adoptable innovations, but also permissive culture. This third element is important because innovation diffusion occurs within a social system; decisionmakers must understand the role of communication channels, time, and the social system itself.

A word of caution is in order: the recommendations below should not be perceived as something done to people, but rather with and for them. As Stephen Chick of INSEAD puts it:

A hypothesis could be that software designers should get away from their computers and do empathic walkthroughs with patients, doctors, nurses and hospital administrators. Then the software might be better designed to address the actual needs rather than the hypothesised needs. The idea would be to shift from a mindset of technology push to one of a design thinking mindset to improve end user focus of those tools. Also, one might argue that it is difficult to change a culture intentionally—that it evolves on its own. Why should the software not be designed to take advantage of existing observations about culture shifts in attitudes about ICT, rather than training to get people to take a new view about ICT?⁷⁸

77 MacKenzie and Wajcman, *The Social Shaping of Technology*.

78 Interview with Stephen Chick.

COMMUNICATE THROUGH MULTIPLE CHANNELS

While mass media tend to be the most rapid and efficient means of informing front-end users about the existence of a new e-health technology, interpersonal channels matter most in the implementation of behavioural change. Notwithstanding the importance of publications in peer-reviewed journals and general media coverage, emphasis must be placed on the pivotal role of near-peer (including patient) experience and attitudes.⁷⁹

Generally, innovations spread faster through similar (or “homophilous”) individuals. But similarity can be a barrier when the homophilous spread of technologies fosters siloed workflows. It can also, however, provide an opportunity to spread innovations across Europe through certain specialties, generating infrastructures and experience on which other services can piggy-back. It is advisable to begin by implementing innovations in hospitals,⁸⁰ which have the financial capacity to act early adopters. Above all, however, they are important hubs of medical education and training and interact closely with surrounding general practitioners and private practitioners. Hence, hospitals can be the epicentre of the spread of innovation.

The opportunities and challenges created by homophily (and heterophily) should be taken into consideration during piloting stages. While homophilous channels provide an opportunity to help spread innovations, they can also widen inequalities if innovations initially spread through privileged channels that are not widely dispersed. The creation of clusters of excellence is also an important prerequisite to innovation generation, as exemplified by Silicon Valley and by MedCity and TechCity in London. To overcome geographical barriers, the Scottish NHS implemented a learning network that offers webinars and online chats in addition to quarterly face-to-face meetings.⁸¹ These sessions are accessible to everyone (even outside Scotland) who is interested in sharing good practices and experiences.

SHIFT THE S-CURVE

Innovations need time to develop and spread. Typically, they spread in an S-shaped curve with a slow adoption rate in the beginning which later peaks and plateaus. This pattern reflects

the diversity of attitudes toward innovation.⁸² Individual idiosyncrasies influence the speed of adoption. ICT-savvy individuals naturally lead the way. In the e-health arena, younger front-end users who are digital natives will likely be quicker adopters than senior healthcare workers and patients (Figure 2 illustrates how discrepancies in Internet competence are currently distributed across European Member States).

Policymakers can promote a leftward shift of the S-shaped diffusion curve. One way to do this is to increase the proportion of innovators and early adopters. Medical students and young doctors are a suitable target group for this strategy: they are in a unique position to take the lead in e-health innovation because many of them have the competitive advantage of already possessing high levels of digital literacy.⁸³

Many medical students and young doctors engage in research, both clinical and basic. It has become fantastically expensive, however, to develop large-scale medical innovations. Large teams are necessary and learning curves for young researchers are steep. ICT technologies are also very complex, but cases of lucrative digital innovations that were initiated by a single individual at a low start-up cost (such as Facebook or Tumblr) are still recent, suggesting that many low-hanging fruit remain to be picked and that e-health may present opportunities for serendipitous innovations that are the digital equivalent of penicillin.

ICT technologies commonly result in winner-take-all outcomes, in which the inventor of a technology that automates routine information-processing jobs makes labour redundant and the inventor hugely wealthy. The invention of tax software that outperformed human counterparts, for example, generated a large value for millions of customers, turned the inventor into a billionaire, and left tens of thousands of tax preparers unemployed. While many tasks in medicine will not be quite so easy to delegate to machines, it is also “easy to underestimate the power of digital, exponential, and combinatorial innovation.”⁸⁴ This reality has strong implications for medical professionals at the beginning of their careers: even if only a few will be the winners who take all profits, workers will surely be paid in the future based on how well they work with robots.⁸⁵

79 Marie-Pierre Gagnon et al., “Systematic Review of Factors Influencing the Adoption of Information and Communication Technologies by Healthcare Professionals,” *Journal of Medical Systems*, Vol. 36, No. 1 (February 2012), pp. 241–277; Yarbrough and Smith, “Technology Acceptance among Physicians.”

80 Abraham, Nishihara, and Akiyama, “Transforming Healthcare with Information Technology in Japan.”

81 Interview with George Crooks.

82 Rogers categorises individuals as innovators, early adopters, early majority, late majority, and laggards. Rogers, *Diffusion of Innovations*.

83 This competitive advantage provides them with a unique opportunity to make themselves invaluable to senior colleagues. Young doctors are not usually able to compete with senior staff in the diagnosis and treatment of patients, because they do not possess the same levels of experience and skills. One study shows that students prescribing emergency drug infusions utilising smartphones can outperform consultants without smartphones. Christopher Flannigan and Jarlath McAloon, “Students Prescribing Emergency Drug Infusions Utilising Smartphones Outperform Consultants Using BNFCs,” *Resuscitation*, Vol. 82, No. 11 (November 2011), pp. 1424–1427.

84 Brynjolfsson, McAfee, and Cummings, *The Second Machine Age*.

85 Wired Staff, “Better Than Human: Why Robots Will—And Must—Take Our Jobs,” *WIRED*, 24 December 2012.

Individuals who are not charmed by the idea of increased technology in their profession or simply feel incapable of keeping up with changes will benefit from incremental innovation. Returning to the example of national electronic health records, instead of designing them to provide a comprehensive set of features, the first phase should cover only basic patient data, including essential emergency information. Once the system has been adopted, its infrastructure can be used to add additional features, such as information on chronic medication, x-rays, and laboratory results. Studies show that once accustomed to a technology-rich environment, healthcare professionals become reluctant to return to pre-digital working environments.⁸⁶ While such labour market forces are important to e-health diffusion, governments must support institutions that are unable to make the transition to ICT solutions on their own in order to prevent the widening of existing divides.

UNDERSTAND THE IMPLICATIONS OF SOCIAL SYSTEMS

It is important for change leaders to understand how to take a differential approach to the “set of interrelated units that are engaged in joint problem solving to accomplish a common goal” in social systems.⁸⁷ “Units” range from individuals to informal groups and major subsystems. They have convergent and divergent interests, are typically formed into structures, and often follow certain hierarchical patterns. In the context of European e-health, for example, different units may be the European Parliament, Member States, their ministries, hospitals, advocacy groups, individual patients, pharmacists, nurses, and doctors.

At the level of individual institutions, multiple stakeholders with divergent needs and demands must be involved. This complicates consensus-building processes, especially when different social units (doctors, nurses, administrators) possess different e-health ideologies, or when existing power struggles are extended onto digital battlefields.⁸⁸ Resistance is not only a symptom of conflicting personal interests; it can also reflect justified concerns regarding safety and efficiency. If constructively integrated into the implementation cycle, these concerns can help reinvent innovations in ways that generate further improvements.⁸⁹ Indeed, policymakers and managers will benefit from the cession of greater ownership to front-end users, rather than reverting to paternalistic top-down approaches.

In short, rather than simply looking at individuals, it is necessary to change the status quo in hospitals at a systems level to support existing personal attitudes and practices maximally and safely. Anachronistic traditions can pose a key obstacle to innovation—many hospitals, for example, ban social media and the use of mobile phones, precluding doctors from using technologies that might improve their clinical decisionmaking.⁹⁰ Some analysts have adapted Max Weber’s typology of social action to promote doctor engagement.⁹¹

Opinion leaders within the various subsystems are key levers of change. Their leadership legitimacy is typically informal; thus they exist across all levels of the formal hierarchy. Formal hierarchies do matter in many hospitals, however, because senior staff can often block change.⁹² Strengthening talented junior staff (e.g., through buddy systems) can help generate buy-in from senior stakeholders to promote meaningful change. More CIO-type leadership positions should also be created in hospitals.⁹³ Strong change leadership, in brief, is a vital factor in the success of e-health implementation.⁹⁴

86 Dobrev et al., “Interoperable eHealth Is Worth It—Securing Benefits from Electronic Health Records and ePrescribing”; Kevin Johnson et al., “Performing without a Net: Transitioning Away from a Health Information Technology-Rich Training Environment,” *Academic Medicine*, Vol. 83, No. 12 (December 2008), pp. 1179–1186.

87 Rogers, *Diffusion of Innovations*.

88 Blake et al., “Driving Health IT Implementation Success”; Gurpreet Dhillon, “Gaining Benefits from IS/IT Implementation: Interpretations from Case Studies,” *International Journal of Information Management*, Vol. 25, No. 6 (December 2005), pp. 502–515.

89 Laurie Lovett Novak et al., “Using a Sociotechnical Framework to Understand Adaptations in Health IT Implementation,” *International Journal of Medical Informatics*, Vol. 82, No. 12 (December 2013), pp. 331–344.

90 Interview with George Crooks.

91 Thomas Lee and Toby Cosgrove, “Engaging Doctors in the Health Care Revolution,” *Harvard Business Review*, Vol. 92, No. 6 (June 2014), pp. 104–111, 138.

92 Steven R. Simon et al., “Lessons Learned from Implementation of Computerized Provider Order Entry in 5 Community Hospitals: A Qualitative Study,” *BMC Medical Informatics and Decision Making*, Vol. 13 (June 2013), p. 67.

93 Hideo Yasunaga et al., “Computerizing Medical Records in Japan,” *International Journal of Medical Informatics*, Vol. 77, No. 10 (October 2008), pp. 708–713.

94 Laurie L. Novak et al., “Mediation of Adoption and Use: A Key Strategy for Mitigating Unintended Consequences of Health IT Implementation,” *Journal of the American Medical Informatics Association*, Vol. 19, No. 6 (December 2012), pp. 1043–1049.

Some EU Member States are earlier adopters than others. And within each state, some subgroups or institutions are more open to innovation than others. Traditional policy frameworks developed for the “paper world” are not always well-suited to the contemporary digital reality.⁹⁵ At the level of national governments and the European Union, more expert interviews, surveys, and comparative studies are required to elucidate and overcome the limitations to innovation that arise from traditional legal frameworks.

Unsurprisingly, e-health is not exempt from the need for trust between stakeholders in change processes. This need includes the trust of front-end users in the ICT producers’ commitment and their ability to provide safe technologies that achieve near-zero failure rates and protect sensitive data as well as citizens’ trust in operational and political leaders.⁹⁶ If large ICT projects fail entirely or exhibit severe data security issues, public trust will erode and citizens will be reluctant to use the new technologies. Unfortunately, ICT projects face regular benefit shortfalls from maladapted systems as well as cost and schedule overruns. ICT providers are not the only ones to blame for these problems; a “democracy deficit” in various health system policies is another important factor affecting trust in e-health ventures. Some past political leaders alienated stakeholders by not adequately communicating with them and by focusing too much on the technological rather than the human dimensions.⁹⁷ Democratic stakeholder engagement is not only a moral imperative; it also yields better outcomes. Open and intense communication across all stakeholder groups and the creation of a common goal and purpose are important prerequisites for change.

Wherever possible, it is advisable to institutionalise the stakeholder discourse among different interests to mitigate collective-action problems (such as the problem of designing open standards for interoperability). While everybody would benefit from ubiquitous participation, it is most efficient for each individual to wait until all others have gone through the learning process and made investments—that is, to wait until good standards have already been developed and tested. Organisations must cooperate fully to agree on standards; an institutionalised collective group can decide what standards to agree on and make them binding on all actors. The next section examines the importance of such standards and explores their significance in overcoming traditional barriers to innovation.

95 Gerard Goggin and Christina Spurgeon, “Mobile Message Services and Communications Policy,” *Prometheus*, Vol. 23, No. 2 (June 1, 2005), pp. 181–193.

96 Stroetmann, Artmann, and Stroetmann, *eHealth Strategies Report: European Countries on Their Journey towards National eHealth Infrastructures*.

97 Goetz and Grode, *Thesenpapier zur Gesundheitstelematik. Ziele, Strategien und Impulse wichtiger Stakeholder für eine funktionelle Gesundheitstelematik in Deutschland*.

5 Focus on Commonalities.

ADOPT AN OUTSIDE VIEW

Implementation strategies must be sensitive to institutional and regional peculiarities. One study states: “There is some convergence of the requirements, functionalities and usability of EHRs [Electronic Health Records] and ePrescribing between different healthcare systems at the points of care between patients and healthcare professionals.”⁹⁸ This observation is the basis for the argument that transferability is limited mainly to principles, tools, and techniques rather than to specific systems. The argument has some purchase: it corroborates diffusion research which suggests that innovations should be re-inventable to allow for local adaptation.⁹⁹

Competing research, however, rightfully warns against adopting such an “inside view,” in which stakeholders believe that their situation is too unique to be compared with similar projects or claim that they cannot simply adopt systems that worked elsewhere. Over-reliance on *ad hoc* approaches does not bode well for interoperability, data portability, and user-friendly solutions; it is usually more costly on both an individual level and to the health system as a whole. The problem with the inside view is that it requires decisionmakers to rely on intuitive prediction, which is prone to biases and contributes to frustrations.¹⁰⁰ The more systems can rely on a body of open standards, the easier it is to connect them. In addition, the more elements can be reasonably standardised, the better their comparability will be, facilitating research and further improvement. Finally, standardisation enables the creation of a broad reference class of similar projects that helps project managers forecast outcomes.¹⁰¹

“It is suggested that more reasonable estimates are likely to be obtained by asking the external question: how long do such projects usually last? and not merely the internal question: what are the specific factors and difficulties that operate in the particular problem? The tendency to neglect distributional information and to rely mainly on singular information is enhanced by any factor that increases the perceived uniqueness of the problem”¹⁰²

Daniel Kahnemann and Amos Tversky

98 Dobrev et al., “Interoperable eHealth Is Worth It—Securing Benefits from Electronic Health Records and ePrescribing.”

99 Rogers, *Diffusion of Innovations*.

100 Bent Flyvbjerg, Massimo Garbuio, and Dan Lovallo, *Delusion and Deception in Large Infrastructure Projects: Two Models for Explaining and Preventing Executive Disaster*, SSRN Scholarly Paper (Rochester, N.Y.: Social Science Research Network, 1 February 2009), <http://papers.ssrn.com/abstract=2229781>; Daniel Kahneman and Dan Lovallo, “Timid Choices and Bold Forecasts: A Cognitive Perspective on Risk Taking,” *Management Science*, Vol. 39, No. 1 (1 January 1993), pp. 17–31.

101 Flyvbjerg, Garbuio, and Lovallo, *Delusion and Deception in Large Infrastructure Projects*.

102 Amos Tversky and Daniel Kahneman, “Intuitive Prediction: Biases and Corrective Procedures,” *Management Science*, Vol. 12, 1979, p. 44.

Essentially, this means that for e-health solutions, there is a tension between the need for adaptability on one end and for standardisation on the other. Any recommendation aiming to maximise adaptability must bear in mind that most healthcare services still function in traditional silo structures where inside views prevail.¹⁰³

All too often, different specialists and professionals do not interoperate well. In many institutions, even nurses and doctors who work in the same departments do not have access to the same datasets.¹⁰⁴ By transforming existing structures, e-health can become a much needed tool to overcome siloed thinking. But this requires more, not less, standardisation. Clearly, psychiatrists have different requirements for an electronic health record system than, say, surgeons. Yet it is also true that many elements are highly similar. Not all areas can be standardised, but more should be.

STRIKE A HEALTHY BALANCE

The high degree of market fragmentation presents a central barrier to continuous e-health development. There are thousands of SMEs offering a wide diversity of products, standards, and insular solutions. The demand side of the picture is similarly fragmented, further compounding the creation of silos and specialised solutions. From an institution's point of view, highly unique systems also create strong dependence on one ICT provider—rarely a situation that an organisation wants to be locked into.

This section has argued that policymakers, managers and—above all—front-end users must stop emphasising differences and must start looking for commonalities. In many instances, it is beneficial to institutionalise the discourse of commonality. For example, the Catalanian Office of Standards and Interoperability promotes shared standards in e-health (see Box 2).

Box 2:

How to Promote Standards in e-Health: The Case of the Catalanian Office of Standards and Interoperability.

The Catalanian Office of Standards and Interoperability is used by agents in the health sector to utilise and promote standards. It relies on five pillars:¹⁰⁵

Training and dissemination: training services through participation in courses, workshops, and seminars.

Terminology: resources related to the semantic interoperability intended to uphold and disseminate the meaning of the information exchanged between systems.

Interoperability: personnel maintaining the interoperability of systems and medical devices using agreed standards as a tool.

Processes: resources identifying and quantifying the benefits associated with interoperability (books, articles, experiences, tools, courses, and conferences).

Accreditation: certification aimed at providers of ICT in e-health which is intended to advise and assist in the approval of products.

¹⁰³ Thomas H. Lee and Michael E. Porter, "The Strategy That Will Fix Health Care," *Harvard Business Review* (October 2013) <https://hbr.org/2013/10/the-strategy-that-will-fix-health-care>.

¹⁰⁴ Ibid.

¹⁰⁵ Carlos Gallego-Pérez, Joan Cornet-Prat, and Josep Manyach-Serra, "Estándares para la interoperabilidad: nuevos retos," *Medicina Clínica*, Vol. 134, Supplement 1 (February 2010), pp. 32–38.

6 Institutionalise Front-End User Engagement.

The analysis so far has focused on informal social structures. In contrast, this section centres on top-level and formal institutional dimensions. Formal institutions matter—they are crucial, for example, to the development of technological standards. Here, early engagement with multiple stakeholders is critical to grasp the various needs and trade-offs for different front-end users. Such inclusiveness creates acceptance through an increased sense of ownership. Moreover, it empowers patients on matters of data security.¹⁰⁶

Stakeholder heterogeneity is an important factor in the delivery of compelling and influential e-health solutions.¹⁰⁷ Experts stress the need to move beyond the “usual suspects” in order to extend healthy years of life in Europe.¹⁰⁸

PROMOTE E-HEALTH INITIATIVES

What can be done to institutionalise the discourse of commonality? Current practices range from grassroots-type initiatives and digital citizens forums, to more formal approaches that either build the scope of existing institutions or seek to establish new institutions with a focus on e-health. This section illustrates these different approaches.

Some European countries have made substantial advances toward commonality. In Germany, for instance, the Federal Ministry of Health launched an “e-health Initiative” to unite key players within the healthcare system with industry stakeholders and research organisations with the goal of identifying existing barriers to telemedicine deployment.¹⁰⁹ And the Federal Ministry of Education and Research launched a *Citizen Dialogue Initiative* on high-tech medicine. Other initiatives involve e-health hackathons, the creation of clusters of excellence, and interdisciplinary start-up retreats. These initiatives are driven by governments, universities, and private entities. An example of a regional cluster is the MedCluster in the Polish Malopolska region, an initiative seeking to foster cooperation among scientists, businesses, and government.¹¹⁰

Britain’s National Medical Director’s Clinical Fellow Scheme represents a different way of institutionalising front-end user engagement. It offers doctors in training the opportunity to obtain top-level leadership experience through a wide variety of projects and placements, ranging from international public health initiatives to local quality improvement projects. This approach is suitable for e-health-related projects; it has the potential to forge highly capable change agents who act as bridges between front-end users and policymakers.

The aforementioned initiatives represent important facilitators of idea exchange between front-end users, designers, academia, and investors. While it is advisable to keep supporting these initiatives, it seems opportune for governments to build on them to achieve stronger, overarching institutionalisation at all governmental levels—the regional, national, and European.

INSTITUTIONALISE E-HEALTH ENGAGEMENT

In an ideal future, ICT becomes such an integral part of healthcare that we cease to speak of “e-health.” Until then, it is helpful to institutionalise the e-health movement.

There is no blueprint for how to pursue institutionalisation. Options range from assigning additional tasks to existing units in the Ministries of Health, to expanding national and regional agencies working on public health and public education, to developing a separate national or European e-health unit altogether. Yet creating new, separate structures at national or regional levels is probably too costly and risks creating unnecessary bureaucracy. Most countries will benefit from strengthening the existing healthcare system. This recommendation is not restricted to government bodies only; nursing and medical associations and patient advocacy groups should also fully integrate ICT in order to give a voice to practitioners at all levels of seniority.

¹⁰⁶ Interview with Norbert Graf.

¹⁰⁷ Dobrev et al., “Interoperable eHealth Is Worth It—Securing Benefits from Electronic Health Records and ePrescribing”; Ian Holliday and Wai-keung Tam, “E-Health in the East Asian Tigers,” *International Journal of Medical Informatics*, Vol. 73 (November 2004), pp. 759–769.

¹⁰⁸ Economist Intelligence Unit—Abott, “Extending Healthy Life Years in Europe”. (21 November 2011), <http://digitalresearch.eiu.com/extending-healthy-life-years/expert-panel>.

¹⁰⁹ Karl A. Stroetmann, Jörg Artmann, and Sarah Giest, “eHealth Strategies—Country Brief: Germany,” *European Commission DG Information Society and Media ICT for Health Unit* (Brussels, October 2010).

¹¹⁰ Cancian et al., “Policy Recommendations for Deployment of Telemedicine Services. Deliverable D3.6, Regional Telemedicine Forum.”

This recommendation reflects the need for a transitional rather than a permanent solution whose ultimate goal is to make itself obsolete by turning e-health into an integral part of everyday routines in healthcare that no longer require dedicated attention.

MAKE INSTITUTIONS MORE SUPPORTIVE OF E-HEALTH

Institutions can support the e-health movement primarily through the development and deployment of knowledge, standards creation, subsidy allocation, and the promotion of an e-health culture. Delegation of these tasks to appropriate institutions can foster e-health innovations that are beneficial to all stakeholders.

Regarding knowledge development and deployment, institutions can commission e-health analyses such as research forecasting to inform decisionmakers in government, business, and academia about these developments.¹¹¹

Studies suggest that there is a need for regulation of e-health content because it can affect patient trust and their interaction with health-related websites.¹¹² Institutions could help orient citizens by:

- directly providing high-quality health information through webpages, smartphone apps or via telephone services (in this way, NHS Choices saves around £67m annually);¹¹³
- rating content quality, establishing a quality seal as an endorsement for good e-health providers (such as health information websites or smartphone apps), and publishing warnings about incomplete or dangerous health advice;
- producing simple guidelines for the public on how to appraise the quality of websites that offer scientific evidence, educational materials, online counselling, and support groups;
- filtering content for compliance and quality assurance before it is made publicly available;¹¹⁴

- generating repositories that allow vendors and institutions to leverage the extensive work that goes into the development of recommendations—e.g., informing e-health content providers on how the content should be formatted in order to provide legislators with trusted information on best practices—thus helping to fast-track further innovations.¹¹⁵

As for subsidy allocation, aside from direct research funding, institutions could also aid the coordination of taskforces and provide recommendations. To help shape an e-health culture, institutions should publicise success stories and distribute awards to e-health champions (as is in Britain).¹¹⁶

Additionally, public scrutiny should be encouraged to deter vendor complacency and promote due diligence.¹¹⁷ Institutions can provide a platform where maintenance costs and frequencies of events per type of user (patient, general practitioner office, large hospital, etc.) are reported. This would help reduce information asymmetries and encourage manufacturers to compete through published metrics. Regulatory bodies could enhance their certification procedures with usability and system availability metrics, as was done in the reporting of adverse drug effects.

At the European level, greater sharing of best practices and data to draw comparisons between different EU Member States is required. Existing e-health benchmarks must be enhanced to instigate competition. Current benchmarks gravitate around adoption; this is important but could be complemented by other factors, such as ease of business for e-health entrepreneurs, e-health research output, digital literacy, and e-health adoption in university curricula. In addition to producing a reflective and comprehensive report, findings could be widely promoted by publishing a ranking that is comprehensible to the general public and useful to the media, thus raising awareness and further mobilising citizens if they believe their countries are not doing enough to provide e-health innovation in the services they desire. NHS England has a blueprint for a “research and learning programme for the open data era in health and social care” (see Box 3) that could also inspire institutions dealing with e-health.

111 Nima A. Behkami and Tugrul U. Daim, “Research Forecasting for Health Information Technology (HIT), Using Technology Intelligence,” *Technological Forecasting and Social Change*, Vol. 79, No. 3 (March 2012), pp. 498–508.

112 D. Harrison McKnight, V. Choudhury, and C. Kacmar, “The Impact of Initial Consumer Trust on Intentions to Transact with a Web Site: A Trust Building Model,” *Journal of Strategic Information Systems*, Vol. 11, No. 3 (1 December 2002), pp. 297–323.

113 Joanna Murray et al., “Use of the NHS Choices Website for Primary Care Consultations: Results from Online and General Practice Surveys,” *JRSM Short Reports*, Vol. 2, No. 7 (7 July 2011).

114 Nicolas Terry, “Regulating Health Information: A US Perspective,” *British Medical Journal*, Vol. 324, No. 7337 (9 March 2002), pp. 602–606.

115 Indrit Troshani, Steve Goldberg, and Nilmini Wickramasinghe, “A Regulatory Framework for Pervasive E-Health: A Case Study,” *Health Policy and Technology*, Vol. 1, No. 4 (December 2012), pp. 199–206. 116 <http://www.ehealthawards.com/>.

117 Abraham, Nishihara, and Akiyama, “Transforming Healthcare with Information Technology in Japan”; S.E. Ross, L.M. Schilling, D.H. Fernald, A.J. Davidson, D.R. West, and Stephen E. Ross, et al., “Health Information Exchange in Small-to-Medium Sized Family Medicine Practices: Motivators, Barriers, and Potential Facilitators of Adoption,” *International Journal of Medical Informatics*, Vol. 79, No. 2 (February 2010), pp. 123–129.

Box 3:

Institutionalising Discourse in e-Health.

The following recommendations constitute a blueprint for the NHS that might be transferable to other countries and areas of e-health as institutions attempt to develop a research and learning programme for the open data era in health and social care.¹¹⁸

Build learning capacity and culture

- Develop an NHS Open Data “Do and Learn Tank.” Unlike a traditional think tank, this organisation would be structured to help launch new projects using lessons from existing programmes and initiatives and to evaluate their results.
- Set up an NHS Data Geek Squad to create a corps of volunteer data geeks and researchers from Britain’s best universities to work with open health data. This could be modelled on Datakind in the United States, or on Code for America.
- Connect research organisations already existing within the NHS, such as NIHR.ac.uk, that are already examining the impact of open data.
- Award prizes to stimulate new solutions to public problems using open health data, as the British and U.S. governments are already doing.
- Develop campaigns designed to promote data sharing and raise awareness about the release of open datasets, their locations online, and their potential uses by the public.
- Set up an open health data academy that trains people to use open health data and measure its impact using online learning, project-focused instruction, and mentoring.
- Fund the creation of NHS open health data fellowships for students and graduates with compelling ideas and practical ways to implement them.
- Develop an open health data mentor network to encourage and train new recruits and younger members of the NHS in the use of open data.

Develop a common assessment framework

- Set up an annual meeting/listserv/monthly hangouts on open health data research to trade best practices and ideas.
- Create a directory (perhaps in wiki format) of other assessment frameworks across countries and sectors. Such a directory would also include a list of key contacts and organisations.
- Use online and offline meet-ups and other approaches to create a culture that encourages knowledge-sharing and collaboration with other organisations.

Stay flexible

- Hold regular “What Works Camps” that connect various users and researchers.
- Ensure that all metrics (especially those designed to measure use and impact) are categorised at different levels and can be analysed separately.
- Continue ongoing research into new and existing approaches to impact measurement. This research effort should be considered a core part of the NHS open data programme.

Share what is learned

- Develop visualisations of how open data has made an impact—for example, through maps that show changes in healthcare quality, efficiency, or cost in different geographical areas.
- Develop an Open Health Data 10, a listing of the ten most impactful uses of open health data.
- Consider providing wikis, seminars, and other means for stakeholders within the NHS to share stories and experiences with open data.

Build a network

- Hold an annual summit to exchange what has been learned.
- Set up an NHS Open Data listserv.
- Consider establishing an external advisory or consulting board of experts to whom the NHS can turn for advice and guidance.

Publish, integrate, and fine-tune the open data conceptual framework

- Develop an interactive version of the conceptual framework that can be annotated.
- Create an expert online advisory network to vet and review the conceptual framework.
- Create channels for feedback and review by various stakeholders.
- Research and evaluate similar frameworks used in other sectors or countries and build on insights or lessons learned.
- Build on the Memorandum of Understanding between the U. S. Department of Health and Human Services and the NHS, and include impact assessment as a joint activity undertaken by these two countries.

Engage stakeholders

- Set up a wiki, forum, or combination of online tools for stakeholders to provide this feedback.
- Develop a subcommittee of the Open Data User Group to focus on health data specifically.
- Hold roundtables with different groups of stakeholders—health-related businesses, advocacy groups, and patient groups—to help shape government policy on the release of open health data.

118 Stefaan Verhulst et al., *The Open Data Era in Health and Social Care* (New York: The GovLab, May 2014).

Box 4:

Case Study: The Estonian Healthcare System?

(This case study is based primarily on an interview with Dr Peeter Ross of the Estonian e-Health Foundation.)

How are the six recommendations in this paper reflected in the healthcare system of Estonia—a pioneer of the modern information society?

1 Close the digital divide.

It is insufficient merely to ask citizens to come to digital services; the services must also go where the citizens are. In Estonia, implementation of e-health services has been part of the government's holistic e-service implementation policy. This can be seen as a best-practice example in taking a citizen-centred holistic e-government approach. From the point of view of the citizen, it is not important which department provides a service or which policy domain the service falls under—what matters is the provision of simple, reliable access to quality services. It is important not to recreate in the digital world silos that exist in the physical world.

The “one-time only” approach to the provision of information by citizens to public authorities, who are then obliged to share it (with the consent of the citizen), nicely matches the citizen-centred approach. Services in Estonia such as e-prescriptions and the nationwide health information system have included a substantial public awareness campaign over the course of several years. The most successful e-health services in Estonia have been those that concentrated on the improvement of the service delivery process, thus benefiting as many stakeholders as possible. This approach emphasises public sector and process innovation, rather than ICT tools or implementation.

2 Enhance ICT training for healthcare professionals.

In 2008, before the implementation of the nationwide health information system, a great deal of attention was paid to the ICT skills training of Estonian healthcare professionals. This was a crucial initial action which was integral to the system's rollout. Very little attention has since been paid to the training needs of healthcare professionals, however. Last year's telemedicine implementation assessment revealed huge gaps in healthcare and public e-health education. This research highlighted several actions that should be taken on the national level to increase e-health literacy. The lack of knowledge of primary and secondary use of data prevents the realisation of benefits from large-scale investments. Potential benefits which could be achieved by new tools and services developed by SMEs will fail to develop if end-user competence and enthusiasm for use of the tools is not increased.

Training in e-health should be a continuous process for professionals. Career advancement incentives could play a part in making such training attractive. The Estonian e-Health Foundation also recommends increasing the e-health literacy of citizens. The combined effect of both efforts could vastly increase the benefits of the digitalisation of health records for both the healthcare sector and individual citizens. Much has been done in Estonia to digitalise healthcare records. The next steps will be to take advantage proactively of the "wellness-medical" convergence, integrating data that citizens are collecting from fitness and wellness apps into digital healthcare records, and to participate actively in cross-border cooperation on the exchange of electronic health summaries and ePrescriptions.

3 Leverage factors facilitating the diffusion of innovation.

Implementation of this recommendation is at an early stage in Estonia, though the strong entrepreneurial culture and early adopter attitude toward e-health and e-government in general provide fertile ground for generating and diffusing innovation in the health and wellness sectors.

The telemedicine assessment mentioned above highlights the importance of e-health support actions, including development of incubators or test bases to analyse new e-health tools and services. This process is at a very early stage in Estonia: only a few strategy papers having been produced and just two small scale e-health incubators currently exist.

Box 4 continued:

④ Shape an e-health culture.

Consonant with its vision of shaping a "digital-by-default" culture, Estonia's approach has been to promote e-health as an integral part of public e-services. Among Estonian healthcare professionals, however, the promotion of different e-health tools and services is very important. This has proceeded in varying fashions, depending on the attitude or specialisation of the particular healthcare institution. A holistic approach has been taken toward the roll-out of e-government services; however, the professional and "corporate" cultures of different institutions remain influential and must be seriously considered in the user-centred approach.

⑤ Focus on commonalities.

Estonia has strongly emphasised the formation of commonalities. In Estonia, e-health services are based on common international data and data exchange standards that are used countrywide. The identification and authentication of all actors is based on a system of common ID numbers and a secure Internet-based data exchange layer ("X-Road") provided by the Estonian state.

⑥ Institutionalise front-end user engagement.

Estonia's approach to maximising interoperability and common understanding of the goals and aims of e-health projects has centred on the establishment of an organisation dedicated to the development and implementation of e-health: the Estonian eHealth Foundation. This organisation seeks to connect almost all of Estonia's healthcare stakeholders, ranging from officials at the Ministry of Social Affairs to hospital doctors and ambulance drivers. Though the formation of a body dedicated specifically to e-health may not be the best approach for all countries, in Estonia this path has proven fruitful and wise.

CONCLUDING REMARKS

How will the medical community respond to the recommendations of this study? Most likely, by questioning why the community should invest scarce time in the dilution of its members' societal impact. Medicine, after all, is already demanding, requiring vast amounts of clinical experience. And keeping up-to-date with scientific developments is difficult even for the most specialised experts.

This challenge—were it to exist—is fair. But it fails to recognise that e-health is not antagonistic to “physical” health; it is, in fact, an extension of the current toolkit of diagnostic gear, medicines, and surgical equipment that is central to traditional modes of medicine. Indeed, the e-health movement aspires, in the end, to render itself obsolete by becoming an integral part of normal healthcare (including health promotion and disease prevention). The path toward this aim must be inclusive: it is important to ensure that those who are most affected by digital innovations are part of the system that identifies challenges and determines which effects are beneficial to society and which ones are detrimental. Innovation in e-health and the systems change it begets should not happen *to* end-users but *with* them. Turning a citizenry of spectators into one of drivers of e-health innovation requires a set of complementary approaches that (a) enhances human capacity (Recommendations 1 and 2), (b) promotes a culture that is permissive of e-health innovation (Recommendations 3, 4, and 5) and (c) shapes institutions that act as catalysts of digital progress (Recommendation 6). It is our firm belief that these strategies act in synergy; an imbalance among them can produce detrimental outcomes. Without strong digital literacy levels to match them, strong institutions may fail to encourage citizens to partake in innovation; they may even turn citizens away from new developments. This is not to suggest that reducing end-user resistance is the key to advancing innovation; the key, instead, is to reduce *misinformed* resistance.

Crucially, pro-innovation enthusiasm requires an attendant societal discourse to ensure that risks and opportunities do not become blurred by the charm of promising possibilities. The essential precondition of such a discourse is the existence of a well-informed and pro-active European citizenry, supported by strong and digitally competent institutions that operate within a conducive cultural environment.

About the Cyber Studies Programme

The Cyber Studies Programme seeks to create a new body of knowledge that clarifies the consequences of information technology for the structures and processes of political systems.

Our research mission is (a) to produce scholarly works that contribute to major academic debates and opinions; and (b) to apply these new understandings in the analysis of major policy problems affecting the security and welfare of states and citizens.

Our teaching mission is (a) to support, guide, and train students and researchers in Oxford and beyond in the work and methods of cyber studies within the subdisciplines of political science; and (b) to foster understanding across technical and non-technical communities to promote the development of this new field of study more broadly.

The Cyber Studies Programme is hosted by the Centre for International Studies in the Department of Politics and International Relations, University of Oxford.

Acknowledgements

The authors thank Atif Ansar, Benoît-Philippe Abeloos, Stephen Chick, George Crooks, Céline Deswarte, Norbert Graf, Sabine Koch, Claus Duedal Pedersen, Kazem Rahimi, Ulrike Rauer, Peeter Ross, and Bendert Zevenbergen for their insights in the preparation of this publication. Any errors in the work are the authors'.

* The information and views set out in this publication are those of the authors and do not necessarily reflect the official opinion of the European Commission. Neither the European Union institutions and bodies nor any person acting on their behalf may be held responsible for the use which may be made of the information contained therein.



European Union
European Social Fund



Investing
in your future

This publication is funded by the European Social Fund
and the Estonian Government