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eHealth Opportunities and Challenges

A White Paper

Gudbjörg Erlingsdóttir & Helena Sandberg (eds.)
Lund University

eHealth Opportunities and Challenges: A White Paper

Gudbjörg Erlingsdóttir & Helena Sandberg (eds.)

Pufendorf Institute
Lund University
May 2016

eHealth Opportunities and Challenges: A White Paper

The Pufendorf Institute for Advanced Studies,
Lund University, Sweden

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eHealth for better for worse, in sickness and in health

Gudbjörg Erlingsdóttir & Helena Sandberg

eHealth is probably the largest wave of change in healthcare since the New Public Management wave between 1980 and 2000. Deployment of eHealth can be seen as a paradigm shift with the aim of providing patients with increased access and influence over their health situation by emphasizing "patient authorization", "patient transparency" and "patient empowerment". Many key actors even see eHealth as a panacea for the impending shortage of healthcare resources.

However, as new eHealth techniques and systems are developed and deployed, both in the public sector and on the private market, new areas of concern and obstacles are surfacing – many of which were not foreseen by the developers themselves. Aspects such as laws and regulations, digital divides, trust, equality and vulnerability issues, changed power distribution, patient integrity and safety, technological security, ethics, the work environment of health professionals, health communication and enhanced transparency need to be addressed to obtain a rich understanding of eHealth.

The above shows that eHealth is a truly multifaceted area that requires multidisciplinary perspectives and discussions to be made comprehensible. The Pufendorf Institute at Lund University offers a stimulating environment and opportunity for such think-tank activities. The eHealth theme at the Pufendorf Institute has gathered 12 researchers from various disciplines, including an international visiting scholar, to contribute to the eHealth discussion. During eight months, from October 2015 to May 2016, this core group met once a week for internal seminars, seminars with invited guests, workshops and lively discussions. This White Paper is the result of this work. Apart from the core group, an extended network of more than thirty junior and senior researchers and other stakeholders outside academia has been affiliated with the theme.

The various contributions in this White Paper mirror the expertise and interests of the researchers in the core group. Accordingly, we do not claim

to cover all possible aspects of the eHealth field. Nevertheless this White Paper presents central components and aspects of eHealth that need to be explored in future research and development; this research could be pursued at Lund University.

Various definitions of eHealth have been formulated by different actors such as policymakers, researchers and entrepreneurs in the field. The research group uses Eysenbach's definition, which refers to eHealth in a broad sense. Thus eHealth is understood as:

> *"[…] an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology." (Eysenbach, 2001 p 1)*

Our main focus is on the state of eHealth in Sweden. Even though eHealth is a rapidly developing global phenomenon, the quite unique organization of healthcare in 20 autonomous county councils or regions, the high degree of digitalization and media technology use in Sweden, together with Swedish laws and regulations, all make it important to first discuss eHealth's opportunities and challenges on a national level.

The White Paper consists of eleven independent texts and an epilogue outlined as follows:

In *eHealth – actors and strategies in the Swedish context* Gudbjörg Erlingsdóttir and Cecilia Lindholm map out the development of the national eHealth strategies, visions and action plans. The authors also describe how the organization of the Swedish healthcare sector affects the development and deployment of eHealth.

In *eHealth and the law* Titti Mattsson presents different aspects of the law that concern eHealth. She highlights legal issues having to do with health data, administrative routines and direct health services, and discusses the need for national legal standards.

Mats Johansson identifies, in *eHealth and ethics – for decision makers*, a number of different stakeholders and moral values, all of which need to be considered when assessing the ethics of eHealth solutions.

In the fourth contribution, *eHealth for everyone?,* Charlotte Magnusson discusses how we can design inclusive eHealth products and services that work well for a wide range of skills and abilities, in varying contexts of use.

In *eHealth from the perspective of media and communication studies* Helena Sandberg and Katherine Clegg Smith outline ways in which media and communication studies can contribute to our understanding of eHealth. They present critical questions that need to be addressed to further our understanding of eHealth, not only as an ongoing wave of healthcare transformation, but of people's experiences of their health and well-being in relation to everyday media practices and media use.

Jonas Borell in *eHealth and work environment – a question of humans, not computers* describes current policies, gives examples of problems found in the literature, and suggests possible ways forward concerning eHealth and the work environment of healthcare professionals.

In *eHealth and the medical profession* Cecilia Lindholm and Gudbjörg Erlingsdóttir discuss the reaction of the medical profession to the implementation of the civic service for patient access to electronic health records. The medical profession questions the transparency that the service leads to, but their reactions differ between different contexts depending on their involvement in the implementation process.

In *eHealth and patient Safety*, Tomas Kirkhorn discusses definitions of patient safety, different models from which strategies of patient safety work can be viewed and shares some ideas about the impact eHealth can have on patient safety in future healthcare.

Charlotta Levay introduces clinical quality registries as an increasingly important application of eHealth in her contribution *Clinical quality registries as eHealth.* Based on a review of previous studies, she suggests that organizational challenges of registry governance represent an interesting avenue for future research.

In *eHealth, a lure or cure for mental health?* Sigrid Stjernswärd describes eHealth from the perspective of mental disorders and mental health care, along some of the associated challenges. She presents examples of research activities in the field and sums up her contribution with areas for further research.

In our final contribution *eHealth and the digital reinvention of healthcare* Martin Stridh discusses how the healthcare system can adapt to and make use of the momentum of the health initiatives in the private sector. He looks in particular at the importance of a planned integration of the private health market into the healthcare system.

eHealth core group at the Pufendorf Institute. (Tomas Kirkhorn not in photo)

eHealth – strategies and actors in the Swedish context

Gudbjörg Erlingsdóttir & Cecilia Lindholm

Efforts to formulate strategies for the development of eHealth services have been underway for more than a decade, on global, supranational and national levels. In 2005, the fifty-eighth World Health Assembly adopted a resolution in which an eHealth strategy for WHO was established; in addition, all member states were requested to plan for eHealth services in their countries. An EU strategy for implementing eHealth services within the European Union was established in 2004, including a call to each member state to formulate national strategies for their work in the eHealth area before the beginning of 2006.

Visions and strategies on a national level

In 2005, Sweden took a comprehensive approach to the development of IT services in healthcare when the Ministry of Social Affairs established the National Board of IT in Healthcare. The origin of the Board was an agreement between the government and the Swedish Association of Local Authorities and Regions (Sveriges Kommuner och Landsting) on establishing close cooperation for development of IT in the healthcare sector. In March 2006 the Board launched and published a national IT strategy for healthcare (Skr 2005/06:139). The formulation of the strategy was partly in response to EU requirements; it was intended to provide support for local and regional work and lay a foundation for intensified national cooperation. The strategy was directed towards five action areas: harmonizing laws and regulations for extended use of IT; creating a common infrastructure; creating a common technological structure; enabling access to information across organizational borders; and making information and services easily accessible to citizens. The main arguments for creating a national strategy were many: the strategy would help enhance the position and influence of

patients/citizens; provide care across administrative borders and geographical distances; provide healthcare professionals with user-friendly tools to improve quality and competence, strive for good resource management and economic efficiency; and create good conditions for IT in healthcare. The document expresses clear appeals for a national direction, coordination and partnership of IT in healthcare.

The first time that the concept of eHealth was included in the title of a national policy document was in 2010, when the Swedish National Board of Health and Welfare (Socialstyrelsen) published the strategy document 'National eHealth – the strategy for accessible and secure information in health and social services' (S2010.020). The change from the former "national IT strategy" to "eHealth strategy" can be explained by a shift of focus from pure development of IT systems to their deployment, use and utility. The scope of the strategy was expanded to include social services as well as healthcare, and its fundamental aim is to create concrete benefits for the individual (that is, the citizen, patient and relative), healthcare and social services personnel and decision-makers in healthcare and social services.

The Centre for eHealth in interaction (Centrum för eHälsa i samverkan, or CeHis; now integrated into INERA, see below) was established in conjunction with the creation of the national IT strategy in 2005/06. The centre's assignment is to coordinate the county councils with respect to the common development of eHealth services, technical infrastructure and rules and regulations. CeHis published an action plan for eHealth 2013-2018 in which eHealth is described as a paradigm shift in healthcare, changing established ways of thinking and requiring comprehensive investments to finance the transformation. The core issue is to increase the individual's possibilities to participate in his or her healthcare and support citizens' involvement in their own health. This is seen as a response to an ageing population and the accompanying increase in pressure on healthcare. Even though the strategy emphasizes the necessity of cooperation and a common development of core services, it clearly states that the responsibility and the decision are in the hands of the county councils/regions and the municipalities.

In March 2016, together with the Swedish Association of Local Authorities and Regions, the Government decided on a new eHealth vision for healthcare and social services. The result, called Vision eHealth 2025, assumes that by 2025 Sweden will be world-leading in using digitalization to promote equity in healthcare and social services. The three main areas

from the eHealth strategy published in 2010 remain in place, and it is stated that the vision will be followed by one or several action plans. The Swedish Association of Local Authorities and Regions is given a leading and coordinating role with respect to the county councils and municipalities. In addition, the vision articulates that the county councils and municipalities have the responsibility to organize, manage, plan, develop, quality assure and fund actions to achieve enhanced digitalization, while the state's responsibility is primarily legislation, supervision, equalization and allocation of resources (p 13).

Implementers on the national level

Two actors on the national level are of particular importance when it comes to the implementation of the national eHealth visions, strategies and action plans: Inera and the Swedish eHealth Agency (eHälsomyndigheten).

INERA is a private limited company; it is owned by the Swedish county councils and regions and governed by a politically appointed board consisting of two politicians from each healthcare region. The company started its activities in the year 2000 and over the years the overall aim of these activities has developed and expanded. Today the mission of the company is to coordinate and provide civic services within eHealth in accordance with the national strategy. Since 2010, and in accordance with the national eHealth strategy that has just been launched, Inera has emphasized that eHealth services have to fulfil several purposes aiming at different groups of actors. The primary goals include accessible healthcare, ways for citizens to safely influence their lives and their health and creating beneficial effects for healthcare professionals and policymakers. The broad mission of the company has led to numerous activities and areas of responsibility, including the provision of healthcare information for patients and citizens, facilitating implementation of patients' digital access to their medical records and creating databases for storing healthcare data. Inera is also responsible for generating regulations for different eHealth services, among which the rules concerning patients' digital access to medical records are some of the most controversial (see Mattsson in chapter 3, and Lindholm & Erlingsdóttir, chapter 8 in this White paper).

The eHealth authority (eHälsomyndigheten) was founded on 1 January 2014 when the former Pharmacy Service Ltd. (Apotekens Service AB)

was liquidated and the new authority took over some of the Pharmacy Service assignments. One main responsibilities of the authority is to develop the healthcare platform HealthForMe (HälsaFörMig), an eHealth service designed to help citizens manage their own health information. eHälsomyndigheten is also assigned to store and distribute electronic prescriptions; produce national statistics for pharmaceuticals; distribute electronic prescriptions across international borders; and quality assure and develop the infrastructure linking healthcare actors and organizations (www.eHälsomyndigheten.se). The HealthForMe platform has been procured but is still under development. When the service is launched the eHealth authority will also become responsible for certifying apps and related services that citizens wish to include in their HealthForMe platform space.

The local implementers

As stated in the eHealth vision for 2025, the county councils and municipalities have the responsibility to organize, manage, plan, develop, quality assure and fund actions to achieve enhanced digitalization. This is a natural consequence of the unique Swedish healthcare model, which implies that geographically divided, politically controlled county councils or regions and municipalities are in charge of both their own economy and the main production of healthcare as well as homecare and social services. The 20 county councils (three of which are called regions) and the 290 municipalities are autonomous; this means that the national level has no means of governing or controlling healthcare activities except through legislation, state subsidies aiming at specific goals and the establishment of public authorities assigned to monitor quality and performance. The national policy documents for eHealth strongly emphasize the need for specific actions; laws and regulations for the extended use of IT must be harmonized, a common infrastructure and a common technological structure must be created to enable access to information across organizational borders and the actors must establish a national direction, coordination and partnership of IT in healthcare. However, the organization of the healthcare sector in individual regions, counties and municipalities has led to a "patchwork" of different IT solutions and structures. This situation complicates the deployment of eHealth, which requires infrastructure standardization – which in turn builds on central planning and coordination. The autonomy of the

county councils and the lack of central governance thus create significant challenges in implementing a national strategy for eHealth.

Future research

The formulation of visions, strategies and action plans will surely continue on a national level and the ambitions to harmonize implementation and regulation of eHealth services will likely remain strong. We believe that this process could and should be attended to by researchers from different disciplines. From a critical perspective it is important to raise questions about the probability of achieving the aims and expectations set out in national visions and strategies. Studies of how the deployment of eHealth services affects efficiency and effectiveness on national and local levels would increase our knowledge and help us optimize the allocation of society's resources. Succeeding with eHealth will require research in a variety of disciplines, including political science, business administration and economics, and methods ranging from discourse analysis to econometrics.

Titti Mattson, Martin Stridh and Sigrid Stjernswärd at the Pufendorf Institute

eHealth and the law

Titti Mattsson

The legal application of eHealth concerns many different areas of the law. This application may comprise various legal issues involving health data, administrative routines, commercial products or direct health services, including clinical activities. However, eHealth also raises legal issues about state obligations and duties of providing healthcare in relation to the individual's personal responsibility for his or her own health, as well as questions about the relationship between the public and the private sector with regard to health-related issues. In the following, I will map out central areas of law that concern eHealth and discuss the problem of adjusting the legal system to the accommodate rapid changes taking place in different parts of the healthcare system, so that it will be possible to sustain basic legal values of privacy, integrity, legal security and non-discrimination.

Health as a human right and a cross-border issue

From the perspective of human rights law, a main issue is the extent to which eHealth services are accessible and of good quality for the population (including vulnerable groups in society). In this context, it is relevant to refer to what the global community has agreed upon when it comes to the right to health, as well as some legal regional commitments to which Sweden is bound. An important landmark in health and human rights is the recognition of 'the right to the highest attainable standard of health' in the preamble of the Constitution of WHO in 1946 (Toebes 2012). Thereafter, several human rights documents containing specific provisions on 'the right to health' have been adopted.[1] In Europe, particularly the European Convention on Human Rights and Fundamental Freedoms (ECHR

[1] Specifically the Universal Declaration of Human Rights (1948), the International Covenant of Economic, Social and Cultural Rights (1966), the Conven-

1950) and the EU Charter of Fundamental Rights (2000)[2] are two treaties that have compelled more regional actions to guarantee the right to protection of health. According to these agreements, any eHealth development must take into account basic human rights principles, such as availability, accessibility, acceptability and quality (AAAQ) as well as legal security, integrity, proportionality and non-discrimination in relation to governmental healthcare activities in Sweden as well as in other European countries.
The development of healthcare as an increasing concern for EU is also of relevance for eHealth in Sweden. Traditionally, a common characteristic for European healthcare systems has been healthcare as a territorial right. Nowadays the Treaty provides that Member States' responsibilities include health management and allocation of the resources assigned to them (Art 168.7 TFEU, Treaty on the Functioning of the European Union). This means that each Member State must offer a universal right to healthcare for those residing within the territory of the state. For eHealth, a consequence of this is that the health sector is no longer based solely on national legislation and that European law and cross-border issues must be taken into account. This means, for example, that eHealthcare providers from other European countries must be treated according to the same conditions as Swedish providers of care, as policy does not allow potential obstacles to the free movement of healthcare service providers.

National legal perspectives on eHealth

Examining eHealth from a national legal perspective requires different areas of the law to be included. A central field is of course health law, which becomes relevant for eHealth issues such as law and medicine, the rights of patients, the rights of healthcare providers and the regulation of the healthcare system. The public healthcare sector in Sweden is founded on

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tion on the Protection o forms of Discrimination against Women (1979), the Convention on the Rights of the Child (1989) and the Convention on the Rights of Persons with Disabilities (2006).

[2] In December 2009, with the entry into force of the Treaty of Lisbon, the Charter became legally binding on the EU institutions and on national governments, just like the EU Treaties themselves.

a goal-oriented framework legislation with the principle of good health for everyone, under equal conditions (The Health and Medical Services Act). Although the legislation states a right to healthcare and hospital care, this right is often not legally enforceable. In other words, the legislation is based on stipulating duties for healthcare providers and professionals, and does not offer individuals justiciable rights. This means that the implementation of new healthcare systems must rely on other forces than rights-based claims from the individual patients, or even from the national government. Instead, the healthcare providers become central actors in this development. Thus, the design of the legislation gives regional and local governments considerable freedom in determining how to organize healthcare in the area overall (Lind 2014). In addition, private care providers have a relatively free market to enter because of the flexibility that the national regulation offers in some areas of the health/healthcare sector. Because freedom of movement in the healthcare sector is integral for EU citizens, there are several key European Directives that facilitate the free movement of eHealth services.

This current legal structure seems to have both advantages and disadvantages for eHealth development. The positive aspect is the possibility of flexibility and unique solutions to meet local needs, and the problem is a disunited eHealth development from a national point of view. So far, the national legislation body has had a fairly passive role in this development. Instead of legislating, the national government has mostly taken on the task of developing overall eHealth visions and strategies as well as initiating other actors on the national level to implement these visions and strategies with semi-legislative tools. Two such bodies in particular have a leading role in this work:. Inera and the Swedish eHealth Agency. (See further *eHealth – actors and strategies in the Swedish context* by Gudbjörg Erlingsdóttir and Cecilia Lindholm). Except for this national policy-making work, local governments and private healthcare providers have shaped much of the eHealth landscape and it seems that they will continue to do so.

Although the private healthcare sector traditionally has been very small in Sweden, it has grown considerably during the last two decades. The eHealth development adds hugely to this growth, as much of these services are provided by the private sector. There are pros and cons with such a development. One advantage is, of course, the likelihood of a broader market and accordingly, an increased possibility to get individually suited healthcare according to one's own wishes and needs. A problem, however, with

the increased diversity of healthcare providers, products and services is the difficulty of getting quality assurance on a national basis and the subsequent risk that the national healthcare system will not live up to the main goals in the legislation for the whole country – good health and healthcare on equal terms for everyone (The Health and Medical Services Act, Section 2).

Another area of the law relevant for eHealth is administrative law, that is, rules that govern the activities and decision-making of administrative units of governmental agencies such as municipalities and county councils. Also here, eHealth-related legal matters may arise in a variety of ways. For example, the eHealth development gives rise to the question of how the e-services development for health services affects the ability of people and groups to access health services and participate in healthcare delivery. In general, the public e-services development seems to fulfil the basic legal goals of Swedish administrative law: *transparency*, *accessibility* and *responsiveness* (Mattsson 2010, Mattsson & Persson 2011). In this context, transparency means exposure to public scrutiny; e-services must also be accessible to anyone at any time or place and responsive to new ideas and demands. Transparency is supported by sharing information with individuals, such as advice, decision-making, case status and health documentation. Health services can also be made accessible around the clock over the internet. Responsiveness is increased by the health services being able to provide individuals with immediate responses. These goals are supposed to be accomplished through easier communication. This type of communicating focuses on quick sharing with and response to individuals, supplying information, applications, grounds for decisions and other individual or public documentation by the government or other agency without the physical presence of persons.

eHealth connects health law and administrative law on one very central issue. Given that eHealth deals to a large extent with the collection and sharing of patient data, it is important to examine how data protection and privacy laws affect these practices. Further research is needed in this field. Traditionally, legislation and practice in Sweden has been given significant latitude for collecting data about individuals – including incapacitated persons. However, the EU new data privacy laws –the General Data Protection Regulation (GDPR) that from 2018 will govern the use and privacy of EU citizens' data – will challenge this data use in Sweden. The new privacy regulation aims to create stronger data protection law for the EU. The GDPR will enable people to better control their personal data and put up legal

barriers for using data without the individual's consent. This is a challenge to Sweden, a country known for its many national registries and mandatory collection of data without consent, and it most likely will also pose a challenge for Swedish eHealth development. Privacy issues are central for the future development of many eHealth services. As a consequence, tools and techniques to ensure that eHealth products and services can provide acceptable levels of privacy are crucial in this regard. Privacy engineering is an emerging cross-disciplinary field within the software and information systems field, with precisely the aim of delivering electronic systems with an acceptable level of privacy.

In addition to health law and administrative law, there is a wide range of other legal issues relevant to eHealth, including contract law, consumer law, employment law, and sometimes even criminal law. In addition, because eHealth is frequently used in collaboration between different care providers (with varying funding and responsibilities), legal issues involving rules on liability for goods and services are another area of concern. Finally, trade and competition law on both national and international levels is relevant, such as the implications of EU-level competition law.

Needs and limits for government control of eHealth development

The delivery of healthcare as a public service is a major undertaking in any society. It requires the state to make many decisions on issues such as resource distribution and priority setting in different health areas. In addition, it requires countries to balance various public and private interests in the course of service provision, especially when a country has given private actors the task of services delivery. The rapid implementation of eHealth solutions in the various healthcare sectors in Sweden reflects many of these issues, and challenges traditional ways of thinking about distribution of resources, priorities, regulation and the role of the private sector in providing public services.

Paradoxically, while there are many areas that raise potentially thorny legal problems, eHealth is still a relatively unregulated area. The legal system is not adapting speedily enough to the rapid changes for healthcare. This needs to be highlighted and discussed on a national level. Healthcare is one of the most information-intensive sectors in society, and there is a

significant need for an adapted legal safety net for the supply of personal health information at different levels and fast information transfer between different eHealth providers. As discussed, privacy protection is essential for safeguarding legal regulation and practice – something that the coming EU Data Protection Directive is intended to achieve.

A more fundamental legal question concerns the relationship between the legal community and the individual. Not so surprisingly, the lack of regulation is at issue here. At times it has been a slow process to introduce many eHealth services because the responsibility at the national level is unclear. The lack of regulation also causes problems with respect to certain areas of eHealth, for example in the case of digital patient records. The regions seem to apply the secrecy rules differently, because the Public Access to Information and Secrecy Act does not really fit the "new order" of online access to electronic health records. Instead, informal rules are decided by the healthcare providers, such as rules concerning parental access to a child's medical journal, young people's access to their own medical records and the individual's access to his or her psychiatry journal. It is time for a review of the Swedish legislation to adapt to the changing situation of online patient records.

In summary, eHealth development encompasses a broad spectrum of legal topics – from the relevance of the right to health, to its practical implications and to health policy and practice, as well as to its relevance from a patient perspective. As a consequence, discussions about eHealth ought to range from human rights issues to perspectives of implementation, content and enforceability, as new issues arise in the national eHealthcare arena. One risk is that definitions of rights, entitlements, obligations and duties may vary greatly among the diversity of actors on the eHealth scene and this will be the object of legal disputes if it is not regulated. However, the need for increased government control through national standards in healthcare must be balanced with the need for local variations and requirements. This is a delicate and difficult task for future legislation-making.

eHealth and ethics – for decision makers

Mats Johansson

Many believe eHealth to be a game changer; they are certain that novel technology and digital solutions will redefine healthcare as we know it. Whether the impact will be that great remains to be seen, but eHealth is nonetheless to be taken seriously. It raises hopes as well as ethical concerns.

An ethicist's job is not to resolve ethical problems, whether these are actual or merely potential, but rather to analyse and bring clarity to them. When it comes to eHealth, however, this is easier said than done. Rapid progress in the fields of technology, innovation and medicine makes it almost impossible to foresee where we are heading. Part of the challenge is that no individual, company, organization or state has control over how things turn out. This means that one cannot entirely rely on intentions, goals or rational plans when trying to identify the specific ethical problems we are about to face.

Everything is not going to change overnight, however. When eHealth solutions are implemented some things will remain roughly the same. For one thing, patients and their wellbeing will still be in focus. In addition, the tools needed to ethically assess eHealth will roughly be the same – these tools have been part of medical ethics for decades. As for the norms, values, and principles often referred to in the context of eHealth, these have been discussed by philosophers for much longer than that.

Below follow some comments that focus on key stakeholders and their various interests, in the context of eHealth. These comments serve to provide a picture of things that politicians and policy-makers, or others leading the development, ought to consider in order to look beyond the hype and hope surrounding eHealth. These comments are by no means exhaustive in terms of what there is to say when it comes to the ethics of eHealth; they touch only briefly on the challenges before us.

Stakeholders

In the present context a stakeholder is (roughly speaking) a person, institution, organization, company, or state, characterized by having certain interests. These interests may or may not overlap with those of other stakeholders, and they differ in kind and in moral importance. That which benefits one stakeholder need not benefit the others. In fact, it might even undermine or harm the interests of others. Thus, there is plenty of room for conflicts of interests.

Certainly, the list of potential eHealth stakeholders is long, including patients, family members, healthcare employees, the industry, citizens, universities, society on the whole, and more. A quick glance reveals tensions between all of these stakeholders. But let's first take a look at those healthcare is all about: the **patients**. It should immediately be said that the term 'patient' is used in a very broad sense. This is because eHealth solutions target not only those individuals who are in need of care, but also healthy individuals. Such solutions can monitor individuals' health, warn when known risks emerge, or simply encourage people to relax and keep in shape. As an individual, one might take an active part here, for example by choosing and using certain apps or gadgets, or being passively targeted by eHealth systems operating in the background (registers and more).

If eHealth fails to serve the interests of (actual and potential) patients, then it fails altogether. Things are complicated, however. Patients (as a group) are by no means homogenous; the group is composed of individuals, and sub-groups, whose interests and needs may differ widely, and who may be affected in various ways by the implementation of eHealth solutions. We must therefore constantly remind ourselves of what should be obvious: that which might be good for one patient need not be good for another. Furthermore, conflicts of interest can also be found "within a person". It is not inconsistent, for example, to believe (though it might turn out to be empirically incorrect) that health records available through the internet will empower patients, by facilitating autonomous decision-making, and at the same time believe that such a system will also contribute to more poor decisions being made.

The **family** also play[s] a key role. In one important respect family members typically share the patient's goal, i.e. wanting what is best for the patient. Sharing a goal is not the same as having the same idea about how to reach that goal in the best way. Disagreement regarding the latter can

have dramatic consequences. Efforts to empower patients might misfire, for example. Allowing patients to access their medical records from any device, at any time, and enabling them to do so through these devices and take a more active role in the care they get, may enable paternalistic family members to take undue control over the patient's situation.

Furthermore, it would be naïve to assume that family members share all goals and interests. Conflicts of interest are to be expected when dealing with lines of action that affect several individuals. eHealth solutions that help very ill patients – those who in the past were hospitalized – to live at home, more often and for longer periods of time, can for example have significant negative impact on the family's quality of life, and on their workload at home. Increased work duties, moral stress, and a perceived responsibility to attend to the patient's care needs can in fact pose a health problem. This is by no means a new risk, but is still worth mentioning when health goes more mobile than ever before.

A third group worth mentioning consists of those who use eHealth solutions for the benefit of patients: **employees in the publicly funded healthcare sector**. This multifaceted group is made up of individuals with many competences. Together they have both expertise and control (they are the gatekeepers). But they are also moral subjects in their own right, with interests and needs. What makes their job easier does not necessarily coincide with what benefits the patients. If a system is very difficult to work with, then it might indirectly pose a risk to patient safety. It is reasonable to assume that employees will benefit from relevant guidelines, which are up to date with regard to the issues that might arise when eHealth solutions enter the picture. It won't do to provide all employees only with a set of very general goals (*värdegrund*); they would need hands-on rules and recommendations relevant to their everyday work.

There are, of course, many other types of stakeholders, including those whose interests and aims are not constituted in a straightforward sense like those of physical persons. This includes **healthcare providers**, **society**, **patient interest groups**, **universities**, and **the industry**. It is well beyond the scope of this brief text to look at these in more detail. Nonetheless, it should be stated that these stakeholders can all be dissected into subgroups, each of which has different interests – interests that must not be confused with each other or with those of the patient or the family. The latter is perhaps most obvious when it comes to the main interest of the industry: making money. If there is no profit to be expected by developing

tools to assist a certain patient group, then the industry will not invest in such development.

Less obvious is that a similar point can be made for society on the whole: that which benefits society in terms of cost-effective care, and increasing tax revenue, may generate losers on an individual level. These conflicts of interests are discussed in more detail below.

The stakes

One needs not only to distinguish between different stakeholders, but also to identify and analyse their various interests. These interests include patient-oriented outcomes such as quality of life (including, among other things, somatic and mental health), autonomy, rights to information and privacy, as well as interests relevant to companies and organizations such as efficiency, knowledge, and profit.

Arguably, politicians and policy-makers should look more closely at the aim to promote **health**, directly or indirectly. Trying to reach this goal includes attempting to increase patients' **life-span**, their **quality of life**, and their **functionality**. Outcomes like these are typically considered valuable for their own sake (intrinsically valuable), and should not be confused with outcomes valuable only as means for something else.

It is important not to limit the discussion to health-oriented outcomes, not even if health is understood in the broad sense described above. There is much more to healthcare than health. First and foremost, we need to ask ourselves whether (and to what extent) eHealth solutions are compatible with basic **rights and liberties**. Here there are risks. Some think eHealth has the potential to **empower** patients, by helping them first form independent, informed opinions in matters that concern their own situation, and then helping them to act on the basis of these opinions. Is this a realistic prediction? It depends on many things, including the time frame we are considering. In the short run, patients will perhaps be better informed about their health and the options available, in relation to how informed they were before the introduction of electronic access to medical records and similar information via the Internet. This requires not only that the information is accurate, but also that the patients are able to comprehend the information and see what parts of the information are relevant to the situation at hand. In the more distant future, however, we might rely more

and more on intelligent systems that monitor our health and lives, and continuously tell us what to do. In fact, this may be the end of patient **autonomy** as we know it. The right to autonomy might still be in place, though not used, so to speak.

eHealth can empower citizens in yet another sense. Up to now, the publicly funded healthcare sector has been pretty much in charge of defining the **alternatives available** to Swedish patients. In the future, much of this **control** will be at the fingertips of anyone willing and capable of using these services, which also will include paying for them. Although this is a global market, it might lead to increased **inequalities** of a more local sort. Clearly, the publicly funded healthcare system will need policies and guidelines regarding how to relate (and interact) with such services, and how to view persons who seek help, based on advice or results bought on that market.

Despite uncertainties concerning the future of eHealth, it is safe to assume that to a significant extent eHealth will involve collecting, storing, processing and communicating sensitive personal data. Hence, **privacy** will be (and already has been) challenged. Several questions arise in relation to the right to privacy: Will citizens have control over their data? Will their data be handled in a safe way? Will they be at risk of suffering informational harm, if sensitive personal data is used to exploit or in other ways harm the person? Will the citizens of tomorrow care as much about privacy issues as people do today (or will they care less, or more)?

Another issue concerns distributive **justice**. Will eHealth solutions be implemented in ways that will ensure the fair distribution of publicly funded health resources? There is a significant risk that some persons will benefit more than others, not because they have a more legitimate claim to do so or because they have greater needs, but because they simply happen to better fit the solutions, platforms, and systems readily available. Here we must not lose track of the question: will the **right** patients get the help they need?

A concern that is distinct from but related to the issue of justice concerns **profit**. As mentioned above, the patients who generate most profit for the industry, directly or indirectly, are not necessarily those who will be helped. Similar to the problem of orphan drugs, we might also have a problem of orphan eHealth – a lack of eHealth solutions that focus on rare conditions, or conditions that will be very difficult to handle, even with the help of such solutions. Again, the industry will need incentives to ensure that they can find solutions addressing those needs.

We have only touched upon the many different values and interests at stake. Many remain to be considered. How for example will eHealth solutions affect the **trust** in the healthcare system? And how will these solutions make us **feel?** It might be the case that we will feel **observed** and **controlled**, when more and more of our daily lives are monitored and analysed by intelligent systems working in the background. As a result, we might feel **guilty**, because we fail to live up to what is expected of us. Or perhaps being monitored will make us feel **safer**, **cared for**, and **important**. How we feel about something is no doubt important, but it must not be confused with how things actually are. We can *feel* in control over our situation, for instance, without *being* in control over it. We can feel cared for, without any person, institution or system caring for us, and so on. Hence, one must always look beyond how patients, family, and others feel about and experience the eHealth solutions they encounter.

Where to go from here?

eHealth will no doubt put its mark on the entire healthcare system. However, whether this is overall a good or bad thing remains to be seen, and it will depend on details not yet known to us. Policy-makers and politicians need to focus on the following:

- What are the most important goals of healthcare?
- In what ways, if any, can eHealth help us achieve these goals?
- Who will be affected by different lines of action, and how?
- Are any groups at risk of being left behind?

Trivial as it may seem, we must constantly remind ourselves that what we *can* do (by means of technology and innovation) does not settle the question of what we *ought* to do. As our ability to create and do new stuff increases, we are confronted with new ethical issues. eHealth is part of that picture.

eHealth for everyone?

Charlotte Magnusson

Design sciences pursue research on the interaction between people, technology and design. Research projects cover innovations of both a technological and social nature, and include design and development of new products (goods and services) as well as new processes (technological and organizational).

eHealth systems can be expected to be used by everyone at some point in their lives. Thus, these systems need to be designed for a wider range of users, with greatly varied skills and abilities. And not only that, but there needs to be a recognition of the fact that not only do skills change with time, but that this is true also for abilities – the person may be ill, stressed, tired or depressed and abilities may also change with age. The population in Sweden and elsewhere is ageing, and many of the elderly persons needing extensive care are over 80 years old. Added to this is the fact that the persons who are expected to use eHealth technology will come from a range of cultural and socioeconomic backgrounds. eHealth systems and devices will also be used in a range of different contexts: indoors or outdoors, at home, at work, or on the move.

Looking at the plethora of systems that are poorly designed, difficult to use and hard to understand, it is quite clear that designing useable eHealth technology that works well for this wide range of skills, abilities and contexts of use is by no means a trivial task. Designing for different contexts of use and a changing user base with varying cognitive and physical abilities is even harder – but is something we need to get right if we want to avoid building eHealth systems that risk excluding a large share of the very persons who should be able to benefit from their existence. It should also be noted that this is not only important for persons using eHealth as patients. eHealth technology that works for a wide range of users and contexts is equally important for healthcare professionals.

Thus we need to build the ability to deal with diversity into our eHealth systems right from the very start. The technology needs to be able to deal

with persons with different cognitive and physical abilities, with different lifestyles, cultural and socioeconomic backgrounds and to follow these persons through their ups and downs. A design that works well when one is healthy and feeling well may be less suitable (or even impossible to use) when one is ill, stressed or depressed. We need to recognize that not only do different persons have different aspirations and abilities, but also that the aspirations and abilities of the same person vary over time, and that they additionally depend on the context the person is currently in.

Universal design, inclusive design

How do we do this in practice? Design philosophies such as *universal design*, *inclusive design* and *design for all* provide part of the answer. Universal design, inclusive design and design for all are terms with different backgrounds – universal design and design for all originate from the built environment and websites, while inclusive design originated within product design. For practical purposes they are essentially the same, and strive to create solutions that:

- Allow people access with dignity.
- Treat people with respect.
- Provide relevant services.
- Are responsive to people's needs.
- Are flexible in use.
- Offer choice when a single design solution cannot meet all users' needs.
- Are convenient so they can be used without undue effort or special separation.
- Are welcoming to a wide variety of people.
- Accommodate without fuss or exception those who have specific requirements.

(CABE, Commission for Architecture and the Built Environment, UK, 2008)

Involve extreme users

Given the complexity of the above, it is important to involve a range of future users and contexts of use in the design process right from the very start. ISO 9241-210:2010 is a standard that outlines the human-centred design process. It is sometimes naively thought that it is possible to ask people what they want, and through interviews and/or focus groups arrive at a well-defined set of requirements that can be used to fully specify the system to be developed. This is rarely the case. When faced with the question "what do you want?", most persons will answer "what can I get?". Thus, eHealth development, just like development in general, needs to be iterative, allowing future users to test and comment during the process.

A challenge when dealing with design for "everyone" is that it is hard to involve everyone in a design process. There are usually practical limitations on the number of persons that can take part in interviews, focus groups, workshops and tests of technology. To widen the scope, it is recommended to look instead at "extreme users" (if this person is able to use the system, many others will too) instead of "average users". Many products are still designed to fit the average person, clearly based on the assumption that a majority of users will be average, and access for persons who lack the ability to use the product has to be provided through special adaptations afterwards (if it is provided at all). In order to design inclusively for diverse persons and contexts, this needs to change. Basic factors to consider are age and gender, but factors such as education as well as social and cultural background can also be expected to play a role. Persons who can be expected to have problems with traditional designs need to be part of the process. Although all persons are unique, it is useful to consider the four big groups of impairments:

- Visual impairments
- Hearing impairments
- Physical impairments
- Cognitive and language impairments

For eHealth in particular, it is also important to note that combinations of these occur, and that combinations do not just add up, but "multiply" (being deaf and blind adds a whole new level of difficulties compared to being deaf or being blind).

There are many ways of involving users. A first overview can be found in the User Study Guidelines from the EU project HaptiMap (2009). It is recommended to use combinations of methods. Each method has strengths as well as weaknesses and will give only a piece of the puzzle. As an example it is important to combine interviews with more practical observations or activities. What people do and what they say they do are not generally the same.

Varying contexts of use

The context of use can have significant impact on what a person is able to deal with (for example, accessing an eHealth solution in a train station will be quite different from accessing it from the sofa at home). To cover this explicitly, the concept of "situation-induced disabilities" has been introduced (Sears, Lin et al 2003), indicating that support for varying abilities and diverse contexts of use may be provided with similar kinds of solutions: For example, large text and good contrast make it easy to see screen elements, for persons with limited eye vision and for persons who find the screen difficult to see because of light glare.

"Easy" is often a challenge

While accessibility is slowly being recognized as something important in public systems, according to Pullin (2009 p 83) cognitive impairments are one of the most difficult and least understood challenges facing inclusive design. At the same time a focus on making a system easy to use also for persons with cognitive impairments (also due to illness, depression, stress etc) is likely to result in a system that is simple for a wide range of persons (an example is the simplified news reports that are also popular among non-native speakers). In addition, following the argument about situation-induced impairments, also easy to use in a wide range of contexts. Thus, cognitive impairments in particular are important to take into account (Fuglerud 2014). A first framework for how this can be done is presented in the licentiate thesis by Johansson (Johansson 2016), who discusses "understanding the nature of the disability", "wide enough margins", "design for extreme users", "design to minimize impairment effects – avoid diagnose thinking" and "take responsibility for the details as well as the

big picture" as key points in his framework. While wide enough margins, design for extreme users and considering both details and the big picture is very much in line with the previous discussion, "avoid diagnose thinking" may seem counterintuitive at first. This recommendation stems from the realization that diagnoses may be useful in a medical context, but might be quite poor tools for predicting what a person is actually able to do. Johansson recommends looking at functioning instead (cf ICF, International Classification of Functioning). Doing so revealed that the participants in the studies presented in the licentiate thesis had difficulties related to:

- Sustaining attention
- Shifting attention
- Short-term memory
- Organization and planning
- Time management
- Problem-solving
- Experience of time
- Undertaking a complex
- Completing multiple tasks
- Handling stress

A list like this provides useful information for engineers and designers, in a way that a list of medical diagnoses does not. It also provides an indication of why it can be particularly useful to include users with cognitive impairments in the user base – many of the points mentioned are problems that will be shared also by persons who are tired (often associated with illness), stressed or depressed. Another observation made by both Fuglerud (2014) and Johansson (2016), which is very relevant for eHealth systems, is that both the login and the system as such need to be designed inclusively. An inclusive system where many users are unable to log in is practically useless.

It should be noted that also for persons with cognitive impairments, the mobile phone can be a highly valued asset. Thus we cannot judge the kind of technology a person might use based on cognitive ability, or for that matter socioeconomic standing – a mobile phone can be something so important that many are prepared to sacrifice a lot to have it – and (as has been seen in media broadcasts) can be the only truly valuable possession of a refugee.

Management and procurement is key

The above considerations need to be taken into account by designers and developers. The importance of usability, accessibility and inclusion also needs to be supported by the management and needs to find its way into the procurement process. Without management support, and without requirements on usability, accessibility and inclusive design in the procurements process (requirements that are also followed up), history shows that the resulting systems are unlikely to be easy to use or particularly inclusive.

Future work

Inclusively designed eHealth is a major challenge. It requires a paradigmatic shift from "designing for the average" to "designing for diversity", that needs to be recognized not only by designers and developers but by management teams and all other parties in the procurement process. Available knowledge on how to do this needs to be taken into account, but as is outlined above, significant research and development of both design methods and concrete designs will also be needed.

eHealth from the perspective of media and communication studies

Helena Sandberg & Katherine C. Smith

In this text we outline ways in which media and communication studies can contribute to our understanding of eHealth. In particular, we will present the types of critical questions that need to be addressed within this field of enquiry to further our understanding of eHealth – not only as an ongoing wave of healthcare transformation, but also of people's experiences of their health and well-being in very broad terms.

The World Health Organization (WHO 2016) defines eHealth as *"the use of information and communication technologies (ICT) for health. Examples include treating patients, conducting research, educating the health workforce, tracking diseases and monitoring public health."*

The WHO definition above conceptualizes eHealth primarily from the perspective of surveillance and action on the part of health-related organizations, but in actuality, eHealth is equally as defined by the use of technology by individual citizens and collective actors who would not typically be considered as part of any official health system. The use of communicative infrastructure for health-promoting purposes represents considerable social change that warrants critical and empirical examination. The field of media and communication studies has established theoretical and empirical traditions that can be usefully applied to this endeavour.

The emerging and constantly changing media landscape

eHealth and eHealth development can be understood within the broader theoretical framework of *mediatization*, a term referring to the establishment of digital internet-based services and the related overall transformation of our media environment. Mediatization is an ongoing social process whereby human experience and social exchange are increasingly 'mediat-

ed'– that is, experienced either wholly or partially through engagement with media technology. Healthcare is but one of several sectors in society that has witnessed a rapid change due to the introduction of new technology and increased digitalization of social life (for example, through social media, online platforms, apps and body media) that is transforming human communication, action and practices (Hepp Hjarvard & Lundby 2015; Hjarvard 2013; Krotz & Hepp 2011)

The new media landscape characterized by transformation and transgression is becoming more complex to study and fully understand. It is more open than ever before, with more flexible infrastructure, as well as free software and protocols that allow new actors to enter professional roles in addition to the traditional audience role. It is now also possible for people experiencing a health issue to find others with similar experiences from around the globe. They can also find health providers, health concepts and approaches from outside of their immediate local and national context. In effect, the internet is a new global "town square" where people from around the world with a shared health experience or concern can encounter one another, learn from each other and in turn have their health experiences and identity shaped through this interaction. The previously clear delineation between the powerful, institutional producers of media content and the relatively generalized media audience, has been replaced by new ways of producing and consuming media content. This development is sometimes referred to as *prosumption/prosumers/prod-users* (see for example Sánchez Martínez & Ibar Alonso 2015; Olsson 2013), meaning that media users are as much producers and consumers of social media (such as YouTube videos on healthy diets or Facebook groups on chronic diseases and other health conditions) as they are consumers of traditional media content. These changes have opened up new ways to produce knowledge about health (laypersons present as experts on health and illnesses as well as treatments) and alter the possibilities for participation in health decisions. We see an example here in platforms that impacted individuals use and produce for themselves and others with similar concerns and experiences (such as the Swedish online cancer community, *'Fuck Cancer'*).

The new media landscape attracts novel actors such as engineers, programmers and entrepreneurs. It also introduces organizational actors to the creation of health-related media – namely health systems and organizations –not previously seen in this arena. Via computer technology, eHealth innovation has introduced non-human actors, data sourcing, algorithms, smart

objects and wearable health devices (such as Fitbit®). These technologies monitor, target and shape our lives in terms of our social reality and everyday practices related to health. In this sense, some eHealth innovations rely on us actually delegating human power to non-humans whose function is to inform us about our own experiences and their possible impact on our health (Lupton 2013; 2012).

Media and communication perspectives on eHealth

Media and communication studies is an expansive field of research seeking to understand the influence of various media forms and channels such as those outlined above. Media and communication scholars are also concerned with the impact of media developments on public life and the effective use of media to create desired outcomes. The field is characterized by widely divergent perspectives in terms of political ideological leanings, as well as between critical and more applied approaches. For this reason, media and communication studies is capable of approaching eHealth from a holistic and not simply pragmatic or institutional perspective.

One aspect worth highlighting in this context is the dividing line between media scholars: researchers interested in the realm of culture and meaning stand in contrast to those who favour material forces and influences. This distinction corresponds more or less to humanistic-versus-scientific, or subjective-versus-objective dimensions of research (McQuail 2005). There is also a distinction between critical and more applied approaches. Critical researchers seek to expose underlying problems, inequities and faults of media practice and relate these to social issues and ideological forces (e.g. Fuchs 2014), whereas applied scholars focus on understanding communication processes in order to solve problems and increase organizational efficiency, and effectively manage social-change processes (Grunig 1992; Falkheimer & Heide 2012). The different perspectives within media and communication studies contribute contrasting ways of posing questions, carrying out media and communication research, and explaining communication processes in society – and these are all methods with potential value for the study (and development) of eHealth.

As a result, some media scholars pay attention mostly to media production, some focus on media content and form, and others concentrate on use. Each of these areas can be studied from a variety of theoretical perspec-

tives within the discipline. Examples of the types of questions that media and communication scholars might pose about eHealth are as follows:

- Who produces eHealth applications and services? What skills and resources are necessary to create eHealth? Where are such skills and resources held?
- What are the prevalent discourses around eHealth in various media and communication outlets? What health issues are of interest to producers and consumers of eHealth? What health issues are ignored? How are health and illness portrayed in eHealth applications and services? How are various actors, roles and relationships portrayed in eHealth applications and services?
- How do various people seek out and engage with eHealth innovations? How does use of eHealth impact the broader experience of everyday life? How does access to and use of eHealth shape our understanding of our own health and the health of others?

A critical analysis of eHealth and eHealth solutions (services) would be well served by taking advantage of the entire spectrum of media and communication research.

A call for research on media users, practices and eHealth services

In the Swedish and Nordic context, media and communication studies has yet to turn its attention fully to issues of health and healthcare, as is the case in other parts of the world. We see few media and communication scholars who are focusing on topics related to eHealth. There is a need for greater empirical considerations of eHealth within a media and communication framework, including the design and communication of health messages, eHealth in the context of behaviour change and patterns of access, and use of media content and platforms that relate to "health" construed in its broadest sense (see for example Forquer, Christensen and Tan 2014; Manganello et al 2016).

We see a growing need within the eHealth field for studies focusing on citizens or media users (patients, family members or the public in the broader sense) and their sense-making of various eHealth solutions and services.

- How will eHealth be domesticized, applied, and integrated into the individual's existent ecology of media?
- How will various digital health content and health services be used and produced?
- How do online consultation and primary care influence our views, expectations, and experiences of the medical profession, and our communication with medical professionals?
- How will eHealth solutions empower patients and influence the individuals' participation in their own health development?
- What does it mean to be a healthy citizen or a patient in the eHealth world?

To conclude, media and communication studies needs to actively approach medicine and health issues as worthy of empirical and theoretical attention. The medical and public health community needs, on their part, to realize that to fully understand the digital transformation of health they must understand the social behaviour and cultural-critical aspects of people's everyday life in a mediatized world.

eHealth and work environment – a question of humans, not computers

Jonas Borell

eHealth and the work environment of healthcare professionals

Work environment research concerns such topics as work organization, the relationships between work, technology and humans, and the health, safety, motivation and productivity of workers. Physical as well as psychosocial aspects are considered. Research and practice in the field typically evolves around examinations of current practice and design processes aiming at improvements. When it comes to eHealth, work environment research may for example concern the study of work environment effects of eHealth solutions or possibilities to use IT to support the work of healthcare professionals. eHealth-related work environment issues often pertain to the psychosocial rather than the physical domain.

In the Swedish government's national vision for eHealth (Regeringskansliet and SKL 2016) three different target groups are pointed out – individual citizens, healthcare and social care professionals, and decision-makers. Here, healthcare professionals and their work environment in relation to eHealth will be the main topic. To date, not much research has been performed specifically focusing on the work environment effects of eHealth solutions on healthcare (Gulliksen et al. 2015). I will describe current policies, give examples of problems found in the literature, and suggest possible ways forward concerning eHealth and the work environment of healthcare professionals. Some examples of interactions with (potential) patients will be given, since they clearly illustrate how the healthcare work environment may be affected by eHealth. A common assumption is that eHealth in the healthcare system should be aimed at supporting professionals' work, augmenting their capacities and providing opportunities to add value. However, as will be shown below, this is often not realized (see Magnusson in this White paper, chapter 5).

The Swedish Association of Local Authorities and Regions (SKL) envisions that eHealth solutions will provide healthcare professionals with the right information at the right place in the right time (SKL 2016). They suggest that direct support to staff can facilitate decision-making, reduce the administrative burden and allow more time for actually meeting patients. SKL also state that eHealth may empower patients and let them take more responsibility, thus relieving the workload on healthcare staff.

The Swedish Medical Association (2014) shares the SKL's notion that eHealth can facilitate the work of healthcare professionals. However, their analysis of the present situation is that healthcare professionals in their work often encounter outdated IT systems that are more frustrating than supportive – if they have access to such systems at all (The Swedish Medical Association 2014; Scandurra 2013).

Successful tests but failed long-term implementations

There are numerous examples of successful test implementations of IT-based support systems in healthcare. For instance, many clinical decision support systems have achieved good results (Garg et al. 2005), often outperforming skilled clinicians in well-defined situations such as diagnosis, although skilled clinicians may be better at ruling out alternative diagnoses (Jaspers et al. 2011).

Computer-based systems to monitor and manage drug risks is another field where promising results have been reported repeatedly (Jaspers et al. 2011). Medication risk management systems can indicate interaction risks between different substances, remind caregivers about significant patient allergies to certain drugs or warn when unusual doses are entered into a system. Reminder systems can keep track of therapeutic regimes and prompt users when a certain drug should be administered, thus avoiding errors due to the human factor.

However, achieving sustainability of IT-based support seems to be a great challenge, as such initiatives often tend to be abandoned after some time (Miller 1994). Sometimes this is due to obsolete information in knowledge databases or outdated decision rules, suggesting that system maintenance needs more resources (Wolfstadt et al 2008), with a special requirement on the combination of expert knowledge in IT and specific medical state-of-the-art technology (Garg et al 2005; Kong et al 2008).

Sometimes failed long-term sustainability results from the systems' poor fit with the actual work contexts where they are supposed to be used (Jaspers et al. 2011; Kong et al 2008), although good results have been achieved during limited test periods. Such mismatches can be in the form of cumbersome user interactions with a system or the poor adaptation of the mode of interaction to situations in which the support is needed, as for example entering text into a computer while interacting with a patient and discussing sensitive health issues. Another reason for failure in lasting use is that healthcare professionals have been reported to lack trust in such tools (Hesse and Shneiderman 2007; Miller 1994).

Interactions between humans and machines

The work environment of healthcare professionals of today is often filled with numerous IT-based systems designed to support or even enable the work to be performed. Ironically, such systems often require more mental resources than necessary from their users and can demand complex patterns of interaction. This increases job stress and results in fatigue and irritation, which may be seen as unwanted side effects of the intention to simplify or enhance healthcare work through IT-based support systems.

As mentioned above, the integration of IT systems in work processes is often poor. Technology-driven development of stand-alone "systems" seems to be able to produce local success for a limited problem space (the space which is studied and evaluated in single projects), but often fails when it comes to more realistic, complex environments with less clear boundaries for the problems they are intended to tackle. The failures are typically associated with work environment issues for healthcare professionals, such as "uncomfortable" user interfaces or lack of trust in the IT systems (Miller 1994; Kong et al 2008). Why does this repeat itself? The failure should not necessarily be attributed to the design processes behind the IT-based support systems as such, since the systems often perform as intended in their design specifications, but rather in the analysis of what is needed and thus in the goals set for system designs. Although much is known about what ought to be included in system specifications, this knowledge is not widely put to use.

A remedy can be to view the design task as concerning the joint sociotechnical system, where the IT-based support systems are viewed together

with the operational, organizational and cultural processes needed to provide care (for example Ludwick and Doucette 2009; Kawamoto et al 2005). If a broader system is considered, including also the people who work with the IT systems and the processes in which work is to be performed, design tasks become more complex, but the chances of actually achieving efficient work and good work environments increase. Such an approach goes beyond tinkering with the interface between an IT system and its human users when problems arise, by setting the goals and designing the processes of an IT system in conjunction with the total work process in which the system is to be used (Woods 1998). The main focus when developing eHealth solutions for healthcare professionals should be on what people can do, not what computers can do. In practice, it might also be relevant to consider the perspective of sociotechnical systems in procurement processes, setting specifications in terms of contextualized functionality instead of pure IT system functionality.

Interactions between people

It has been reported that Americans have greater trust in their physicians than in health-related information found on the Internet (Hesse et al 2005). As a consequence, (potential) patients approach their healthcare organizations for advice regarding information they have found online. The vast availability of medical and health-related information that people can access freely and on their own thus contributes to a greater demand for contacts with healthcare professionals, who may experience more job-related stress.

Historically the virtual monopoly of healthcare professionals regarding general medical knowledge and specific information about individual patients protected these professionals from scrutiny and questioning. Some studies have reported that healthcare professionals experience a threat to their authority when patients contribute information found online (see for example Broom 2005). Shifts in the power balance between healthcare staff and patients, with new demands stemming from web-informed patients, may increase job stress for healthcare professionals (Wald et al 2007).

A recent Swedish study reported that more than half of the physicians included were asked by their patients for advice about health care apps (Zhang and Koch 2015). This is another field, in addition to tradition-

al medical expertise, where healthcare professionals need to stay informed and up to date. Thus eHealth solutions, intended to improve individual health and wellbeing and ultimately contribute to effective and well-targeted healthcare in society, may entail extra tasks and increase the burden and stress on healthcare professionals.

Similar effects have been reported in relation to digital medical records, when patients have easy access to their own, personal information. Such access has been reported to transform the patient-professional relationship (McGinn et al 2011). The introduction of online access to one's own medical records, intended to empower patients and invite them to participate in the decision processes concerning their health, has been reported to induce high levels of stress in healthcare professionals and provoke significant professional resistance (see for example Erlingsdóttir et al 2014).

With more informed patients and an increase of patient involvement in decision processes in healthcare, the work environment of healthcare professionals changes dramatically. These changes require a re-negotiation of professional boundaries and of the patient-professional relationship, which may bring significant job stress and should be managed carefully (see Lindholm & Erlingsdóttir, chapter 8)

Summing up and moving ahead

All of us have experienced frustration when using digital artefacts that we did not immediately understand how to operate. For healthcare professionals, bad interface designs can have great impact, adding stress, frustration and mental exhaustion at work, with implications for patients as well as the health and wellbeing of the staff. Fortunately, the general knowledge about cognitive ergonomics, interaction design and user experience-centred design processes has taken great steps in recent years. If put to use in the field of eHealth, many of today's problems with IT-based support systems for healthcare professionals may be remedied (see Magnusson, chapter 5)

Still, the real potential with eHealth and the possibilities offered by digitalization and automation require more than gradually replacing isolated manual tasks with machines and streamlining user interfaces. Hesse and Shneiderman (2007) suggested that eHealth development should move from isolated technical solutions to look instead at how advanced computing and telecommunications could be used in conjunctions with existing

systems of care to ensure that people live longer with lives of higher quality. Their suggestion might be interpreted as considering a larger subsystem rather than a single task or functional part of the existing health care system when developing IT-based solutions. Doing so may increase the opportunity for improved efficiency and provide possibilities for avoiding some pitfalls of user interactions with artefacts.

A further step ahead might be to consider redesigning entire systems of care, to fully utilize the potential of eHealth and achieve proactive as well as remedial health effects. If not only separate parts of the present sociotechnical system for health care are updated or changed with the help of IT, but instead the whole system design is changed to make real use of the possibilities with IT, there is great potential to deliver better results and higher efficiency (see also Stridh, chapter 12) – but the stakes are high. Such a radical approach would have vast impact on, for example, the healthcare professions, separately and as a system. With changing competence needs, power balances and mandates have to be renegotiated. The major transformations of the professions that would probably be required may bring conflicts that impair the work environment of healthcare professionals – due to eHealth (see also Lindholm & Erlingsdóttir, chapter 8).

Based on the discussions in this chapter, future work environment research should focus on:

- Design processes that contextualize IT-based support systems as parts of larger sociotechnical systems
- Strategies and methods for specifications of sociotechnical system performance in procurement that is intended to improve eHealth
- Effects on the work environment of healthcare professionals from eHealth solutions aimed at patients
- The work environment effects of eHealth-related development, for example concerning changes in the landscape of healthcare professions

eHealth and the medical profession

Cecilia Lindholm & Gudbjörg Erlingsdóttir

In Sweden, as in many other European countries, public agencies have promoted the expansion of eHealth in the form of civic services. One of the strongest arguments for this type of services is to enhance patient participation and patient empowerment. The development is considered part of a more comprehensive movement, emphasizing patients' rights – including options to make far-reaching decisions about care and treatment.

In this section, we focus on one of the most important civic services within the development: the patient's online digital access to his or her electronic health records (EHRs). Despite its importance, or maybe because of it, this service has been one of the most controversial in Sweden so far. The launch caused concern and in some cases strong negative reactions among medical professionals. Such access constitutes a specific part of the digitalization of the patient-doctor relationship, with particular potential to transform this relationship as the patient is included as an intended user of the health records (Wintereik et al 2007).

Patient online access to EHRs – two implementation processes

We have conducted studies on the development and implementation of patient digital access in Uppsala County Council (UCC) and Region Skåne (RS) and the research continues as the service is gradually introduced in different parts of their respective healthcare organizations (Erlingsdóttir & Lindholm 2013; Erlingsdóttir Lindholm & Ålander 2014; Erlingsdóttir & Lindholm 2015; Petersson & Erlingsdóttir 2016).

In November 2012, as the first of the 20 county councils and regions in Sweden to do so, UCC opened the EHR system to patient access. In 2014 RS was the second implementer of the civic service. By the beginning of 2016 approximately half of the county councils and regions had begun offering the service to their citizens, and the rest are planning for implementation in the near future.

The implementation process and the reactions of professionals, especially in the medical field, differ considerably between the UCC and RS. In the UCC a deep conflict arose between the local medical association and the county council just as the service was to be implemented in 2012. The launch of patient digital access was even postponed for six months when this conflict became untenable.

In the RS the implementers were aware of the problems that had occurred in the UCC, and were determined to avoid a similar situation. Thus, they made sure that representatives for the medical profession took part in different parts of the implementation process, for example concerning adjustment of the regulation of the service in the RS. The already formulated UCC regulation served as a model, but it was adjusted to meet local needs as well as the opinions of the medical profession. Among other things, it was agreed that no entries in the EHR written before the day of the launch would be visible to patients. This was a requirement from the medical profession, as it was considered important that only those entries written by the medical professionals who were aware that patient access was operational should be accessible to patients. This does not imply that there have not been any negative reactions in RS, but the type of conflict that arose in the UCC was avoided in RS.

The medical profession's main arguments against patient access

Despite the differences in implementation processes, the arguments of physicians are similar in both county councils. Studies of the deployment in the UCC and RS show that the medical profession mainly disputes claims of transformed and enhanced transparency initiated by patients' digital access to their health records (Erlingsdóttir Lindholm & Ålander 2014; Erlingsdóttir & Lindholm 2015; Grünloh Cajander & Myreteg 2016). The main source of disapproval is the long-standing notion that the patient's health record is a working tool intended for use only by professionals, and that patient access constitutes challenges, and even threats, for several reasons. Below we discuss the three most important arguments against patient access to the EHR systems, as they were revealed in interviews with RS and a survey of UCC medical professionals.

Argument 1: Patients' digital access to their EHR will increase the risk of formal or informal complaints from patients. A common reflection from the interview and survey respondents was that patient access will result in an increased risk that professionals will have to answer to patients who question the information entered in their EHR – a development that the professionals considered both time-consuming and frustrating. Some of the respondents argued that the patient-doctor relationship will become "juridified", stressing that "the system is judicially insecure"; "the health record has become a legal document" and "the patient will look for errors and mistakes". Several respondents emphasized that patients may sometimes find health record information offensive or unpleasant, but that this information nevertheless constitutes important information for other healthcare professionals. A commonly referenced example is an entry in the EHR saying that the patient is suffering from obesity or is living in a destructive family environment.

A related argument is that patient access will result in an increased number of questions or requirements for further explanation – activities that the medical professionals consider too time-consuming and unnecessary.

It is not merely the content of the EHR that causes concern among the professionals, but also at the point in time at which the content becomes accessible to the patients. Both county councils allow the patients immediate access to the EHR, that is, even before the entry is proofread and verified. Several respondents express strong reactions to this practice, arguing that it deprives them of the opportunity to correct mistakes or could even make them responsible for other people's mistakes (such as typing errors made by the medical secretary).

Argument 2: Patients do not have the required knowledge to understand the information. This argument pivots around a perceived risk that the patient, due to lack of knowledge, will misunderstand and/or be harmed by the information in the EHR. One potential situation, frequently discussed by the respondents, is that a patient may interpret an early reflection on a possible diagnosis as the "final verdict". In these cases, the patients' lack of knowledge causes unnecessary harm that could be avoided if the physicians had the opportunity to explain the situation in a language adapted to laypeople. A related argument is that a patient who finds a diagnosis such as terminal cancer in her/his medical record may face a situation where she or he is

alone and unable to ask questions. Some of the respondents emphasized that providing such information in a way that reduces the patient's anxiety and stress is part of their medical training.

Argument 3: The communication among professionals will be affected. Some respondents had concerns of a different nature: that the inclusion of patients in the expected group of readers will increase the risk that the professional language may become simplified and stringency will decrease; this development in itself increases the risk of medical malpractice. The respondents argued that patient access means that physicians need to explain medical terms, such as Latin expressions commonly used by medical professionals, in lay language. Again, this was considered to be time-consuming and unnecessary. Several respondents also assume that medical professionals will start to use other means of communication, not accessible to patients, such as undocumented meetings or hard-copy shadow records.

Discussion

As early as 1985, Freidson predicted that enhanced computerization would make knowledge more accessible to everyone and transform patients into consumers of healthcare, more apt to actively question and even challenge professionals (Freidson 1985). The status of professionals is dependent on a significant knowledge gap between professionals and laypersons, which, perhaps paradoxically, is expected to create trust in the professional-layperson (doctor-patient) relationship (Freidson 2001). As patients gain access to information that previously was more difficult to reach, their knowledge and their ability to question and control the professional's judgement increases, meaning that the professionals' privileged position and their power over the information in the EHRs will decrease (Walsham 2001). The logic is thus that the knowledge gap reduces trust within the patient-doctor relationship, initiating a process of deprofessionalization. This might explain why some professionals feel threatened by patient online access to the EHR.

On the other hand, Checkland et al (2004) argued that the former adage "trust me, I'm a professional" is obsolete in today's society. Checkland et al emphasize that direct access to information over the Internet may contribute to enhanced trust in the patient-doctor relationship as the patient becomes knowledgeable and enlightened. How online access affects

the patient-doctor relationship in Sweden has not been studied to any large degree so far, but there has been a review of articles and reports describing the effects of patient access on doctors and patients in the US (Mold et al 2015). This review shows that a majority of the physicians experienced enhanced trust from and strengthened relationships with patients. The academic debate thus far shows that the effects of implementation of patient access to the EHR might be complex and that the service could both strengthen and weaken the doctor-patient relationship. However, digital access to the EHR enhances patient empowerment as well as transparency, which gives the patient the opportunity to be an active and participating actor instead of a passive patient. Medical professionals might thus need to explain and justify their actions and decisions to an enlightened as well as controlling patient to a greater extent in the future.

Another important aspect is that professional groups may feel cheated when they are not invited to take an active role in negotiating how new technologies should be interpreted and used (Eriksson-Zetterquist et al 2009 p 1151). This might explain the difference between the reactions of medical professionals in the UCC and RS. The medical professionals in RS were active to a larger degree in the negotiation of how the technology should be interpreted and used and were thus more at ease with the implementation.

New problems and possibilities created by the encounter between the medical profession and the digitalization of healthcare can be anticipated as more digital services for all are developed on the Internet (see Woodman et al 2015). One example is the Internet site PatientsLikeMe (PLM) which is designed for patient's independent use to obtain information and knowledge about their condition, and to come in contact with other patients with the same diagnosis in order to share experiences (Petersson & Erlingsdóttir 2015). Traditionally, the knowledge base of the medical profession has been seen as "specific and difficult to gain for actors outside the profession" (Jonnergård & Erlingsdóttir 2012 p 682). However, the professional knowledge base is based to a large degree on the information that a physician gains from treating patients over time. This information can now not only be shared with the doctor but with other patients on Internet sites like PLM. This and other online information on medical conditions give the patient a knowledge advantage about their specific condition in relation to their doctor. This in turn may lead to a change of the power balance in the doctor-patient relationship (Petersson & Erlingsdóttir 2015). The bottom

line here is that it might not only be the professionals' working tool but also their knowledge base that they must share with patients.

Future research

eHealth services are being developed and implemented at an increasingly rapid pace and studies of the experiences of both medical professionals and patients are still rather rare. This may depend partly on the fact that because services need a period of adjustment after introduction/implementation, some studies are not meaningful to perform until after a certain period of time. There are thus several studies that are waiting to be done. We also need studies from different countries and contexts; both patient and professional cultures are quite context-bound. On the whole there is a need for longitudinal studies that can enlighten us in the area of eHealth services' effects on both patients and professionals, but also their long-term effects on the relationships among professionals and the patient-professional relationship.

Coordinator of the eHealth theme Gudbjörg Erlingsdóttir.

eHealth and patient safety

Tomas Kirkhorn

Present state of patient safety

From a patient point of view, safety in healthcare is something we presume to be self-evident: the moment we contact or enter the healthcare system because of illness or injury, we count on being taken care of in a safe and secure way – a way which does not cause additional illness or new injuries. However, studies from many countries in the developed world estimate that approximately 10 per cent of all patients in inpatient care are subject to healthcare-associated harm, that is, preventable harm due to inadequacies in healthcare procedures. The term *preventable harm* indicates that the harm is not associated with a known calculated risk from a procedure; nor is it a direct consequence of a patient's severe condition. According to a recent report from the Swedish National Board of Health and Welfare (Socialstyrelsen 2016), the most frequent kinds of preventable patient harm in somatic inpatient care are healthcare-associated infections, harm associated with surgical procedures, drug-associated harm and pressure ulcers (Socialstyrelsen 2016). The same report states that the time spent in care doubles in average for patients who suffer healthcare-associated harm. In addition to the suffering for the individual patient, this also has tremendous economic consequences. The cost of caring for patients with healthcare-associated harm is estimated to be approximately 10 per cent of the entire healthcare budget. This situation is indeed a great challenge.

The question of the impact that eHealth has and will have on patient safety in the future does not have a simple, general answer. Like other new technologies, procedures and tools that are introduced in healthcare to improve quality and safety, many eHealth solutions will make a positive contribution. However, each solution needs to be studied in its context, and in relation to its actors involved – the patients and the caregivers – so that no new risks will be introduced as a result of lack of knowledge or experiences in working with these new tools. The aim of this paper is not to give a detailed answer about the extent to which eHealth can

contribute to a better patient safety situation; it emphasizes the need to better understand the complexity of safety problems we must deal with in the healthcare system in which eHealth solutions will be continuously integrated. One important lesson from the efforts of recent years to create safer healthcare is that there are very few, if any, quick fixes.

Definitions and models

Before we go any further we will look at the definitions of "patient safety" and how this definition influences our perspective on the issue. According to Swedish legislation patient safety is defined as "*protection against patient harm*", and according to the World Health Organization it is "*the absence of preventable harm to a patient during the process of healthcare*" (Patientsäkerhetslagen 2010; WHO 2016). As already mentioned the term *preventable* indicates that the harm is not associated with a known calculated risk from a procedure, and is not a direct consequence of a patient's severe condition as such. According to the Swedish legislation, the definition of patient safety includes not only physical injuries but also suffering and psychological harm (Patientsäkerhetslagen 2010).

From the above definitions of patient safety, a great deal of patient safety work has focused on preventing harm from occurring, that is, work has been aimed at non-events. With this approach it is natural to invest time and consideration to examine situations when things go wrong, or might go wrong. By using traditional risk and event analysis, we search for root causes and efficient actions to prevent these events from happening in the future. Although we can gain valuable knowledge from analysing adverse events, this approach is grounded in the assumption that to a major extent, these events happen as a result of a clear relation between cause and effect: if the right prerequisites are at hand, it is possible to choose and follow the "right" path and end up with a successful or accepted result. This view of managing risks and safety has been referred to during recent years as Safety-I (Hollnagel et al 2015). Within healthcare, this strategy might be valid in certain cases characterized by a strict relation between cause and effect, but it will definitely not apply in a majority of all cases. However, despite the conceptual limitations of applying Safety-I to healthcare, a significant amount of patient safety work has been based on this model, using traditional risk and event analyses in order to prevent unwanted things from happening.

With its increasing levels of specialization, interactions among many actors and involvement of new technology and procedures such as eHealth solutions, the healthcare of today and tomorrow constitutes a complex system. Thus by definition this system is impossible to fully predict. The outcome of a procedure, from a patient safety point of view, depends to a great extent on the *inherent state* of the system and all its actors. This inherent state varies continuously, and is often not known or evident at a given point in time. In such a system the presumption of cause and effect will not be sufficient. The strategy of putting proposed, separate actions into place might even create a false sense of security.

Instead of focusing on situations when things go *wrong*, an alternative and complementary point of entry for patient safety work is to focus on why things go *right*. We know that 90 per cent of all patients will get treatment and care without any harm. Although these successful outcomes are the result of a combination of routines, work procedures and other system components put into place to strengthen safety, the awareness and capability of the healthcare professional to adapt to the present situation plays an important role. This perspective on safety is referred to as Safety-II (Hollnagel et al 2015). An important concept in Safety-II is that things that go right happen in precisely the same system as those that go wrong. The outcome is less dependent on the right prerequisites and more a result of the system's ability to respond to the variations that are present in everyday work. These variations may be of both a quantitative and qualitative nature, such as variations in available resources or patient flow, and variations in patient needs or abilities to contribute to the care procedure. Some variations are unwanted and should be reduced, while others are natural and not possible or meant to be controlled; still they must be dealt with. Therefore, in order to maintain a desired level of safety, different strategies must be developed to identify and relate to variations, in addition to means and methods for creating a flexible and resilient system.

The components and ideas on which the Safety-II concept is built have similarities to those found in Profound Knowledge of Improvement, which was described by Deming (1993) and transferred to healthcare by Batalden and Stoltz (1993). According to this improvement knowledge, it is suggested that in addition to the traditional professional knowledge areas, four basic and essential ingredients are required for successful development of quality and safety in a healthcare organization: (1) knowledge and under-

standing of the system and work process, (2) understanding of variation, (3) learning-based improvement and (4) psychology of change.

So what impact will eHealth have on patient safety?

Let's return to the issue of the impact that eHealth is having and will have on patient safety. The development of eHealth solutions aimed primarily at improving the support given to individuals (patients), healthcare professionals and healthcare management. These different kinds of support are mainly available through new and extended electronic communication and information transfer among and between the actors involved in health care provision. As in most cases, access to correct information at the right moment is crucial for the decisions taken and actions performed among and between healthcare professionals and the patient. From what we know about adverse events, deficient communication and information transfer – on their own or in combination with other causes – contributes to more than half of all adverse events. The outcome of communication relies on many components, such as the correct formulation, transmission, reception and understanding of the information. Depending on the actors involved, and where in the communication chain weaknesses appear, the result can vary greatly. Points of weakness include from unsafe or deficient information transfer between individuals, (for example when reporting patient status or needs for care), or lack of information due to systems that do not interact optimally with one another or their users, (for example when essential data on status or needs are not easily accessible at the very moment when they are required.

In this respect eHealth solutions can play an important role for safety, through improved collection and presentation of data. Allowing patients to self-register data connected to their situation, illness or injury with the intention of sharing this data with the caregiver is one of many near-patient applications that eHealth can offer. Self-registration gives the patient a possibility of increased participation and, to a certain extent, control in the care procedure, while it provides valuable data to help make decisions about medical treatment, future care and rehabilitation.

Increasing use of eHealth solutions will engage and affect both the individual (patient) and healthcare professionals. From a patient safety per-

spective, eHealth solutions can be regarded as one of many new or changed procedures that will be introduced in the complex world of healthcare. As discussed above, work with safety in complex systems is challenging and it requires thorough and continual study of the system, its state and the interactions among its actors. It is essential to define the goal for the procedure in question. When this goal is clear, we can start identifying and monitoring factors that will affect the achievement of that goal, such as variations and known risk situations. When introducing new technology and entering new environments, we must not forget to use established factors of success (why things go *right*) gained from earlier experiences, for example from what we have learned about safe communication between the parties involved. We definitely need to take advantage of the knowledge gained from analyses of adverse events (when things went *wrong*) and risks, but we must also put more effort into understanding and developing the work process. Thus, although the two discussed concepts of Safety-I and Safety-II differ in focus, and this basically leads to different working methods, they both aim at a common goal: to create a safe healthcare for patients. Safety-I and Safety-II do not exclude one another; rather, they can and should coexist.

Looking ahead

To conclude, eHealth solutions as new tools or procedures do not solely or automatically contribute to a higher, or a lower, level of patient safety. Any change in a process or procedure does not automatically result in an improvement; in this sense, every eHealth solution must be studied and considered through the lens of the patient-safety microscope. It is a challenge that requires open minds, mutual respect, and collaboration between users and developers of these solutions. The ultimate goal for new methods and solutions in healthcare, with or without the *e*, must be to create increased value for those healthcare is intended to serve: the patients.

Clinical quality registries as eHealth

Charlotta Levay

Introduction

National quality registries are key to healthcare quality policies in Sweden, and there is a growing interest in this kind of registries in the US and elsewhere (Levay 2016). Quality registries are databases with systematically collected information on problems, treatments, and outcomes for patients who have a certain disease or undergo a certain treatment. For instance, there are quality registries for diabetes care, gallstone surgery, and intensive care. Such registries and ones like them are also called patient registries, medical registries, disease registries, clinical databases, or clinical audits. They comprise several provider organizations and many have countrywide reach.

When they work well, quality registries serve as platforms for monitoring and developing quality of care for their respective group of patients. They allow participating organizations to benchmark their quality against others, follow up their improvement efforts, and collaborate with other participants. Data from well-functioning national quality registries are also used for other important purposes, including clinical research, public quality reporting, and information to stakeholders and policymakers.

Internet and related technologies are used extensively to collect, analyse, and display registry data. Data are typically submitted online or through automated extraction from electronic health records. Several Swedish registries offer interactive data analysis to participating providers, and some offer online comparative indicators of quality of care to the general public. Other types of eHealth, such as electronic health records, facilitate the development of quality registries, and registries can in turn stimulate and encompass other types of eHealth, such as decision support systems for patients and clinicians. All in all, contemporary quality registries can be viewed as focused applications of eHealth that interact with other established and emerging applications.

Previous research about quality registries

Data from quality registries are used for medical, epidemiological, and health economic research purposes, such as evaluating the effectiveness of interventions or the equity of healthcare services. In addition to research *using* registry data, there is also research *about* registries. Most of it consists of studies and commentaries in medicine, information science, and health policy regarding the proper design and operation of clinical registries. Several studies present features and accomplishments of particular quality registries (see for example Malchau et al 2002; Larsson et al 2012; Carroll et al 2015), and several commentaries discuss the usefulness of such registries more generally (such as Black 1999; Dreyer and Garner 2009; Lagasse 2012). A few studies evaluate registries as a method for quality improvement (including van der Veer et al 2010; 2013), while others deal with the important topic of data quality and how to achieve it (for example Arts et al 2002). Much of this research is summarized in a regularly updated handbook on patient registries published by the US *Agency for Healthcare Research and Quality (AHRQ),* with a separate chapter on registries for quality improvement (Gliklich et al 2014).

From these writings, it is clear that setting up and managing a reliable quality registry is a complex venture that demands collaborative efforts among a diverse set of actors, such as professional societies, hospital departments, patient associations, government agencies, and the pharmaceutical or medical device industry. Even well-designed registries can succumb to lack of financing (Lagassse 2012), and even multi-faceted improvement programmes based on registries can fail for unclear reasons (van der Veer et al 2013). Operating a useful quality registry apparently involves considerable organizational challenges in terms of mustering engagement from a variety of actors.

There is also research on quality registries conducted from social science perspectives. Some studies identify barriers and facilitators to the development and use of quality registries. They suggest that in order for actual quality improvement to materialize, local healthcare professionals must cooperate within and outside their local context, with sufficient resources and in collaboration with administrative and political levels of decision-making (Eldh et al 2014, 2015; Fredriksson et al 2014). They also suggest that conditions for developing registries vary considerably between countries,

depending on distinctive regulatory frameworks and quality policies (Sousa et al 2006; Levay 2016). These studies suggest that there are important social and organizational contingencies to the successful operation of quality registries.

Some social science research looks at individual registries to explore topics such as innovation and research collaboration. Studies of the Swedish Rheumatology Quality Register describe it as a platform for emergent, practice-driven change (Essén & Lindblad 2013) and for transfer, translation, and transformation of knowledge across different types of barriers (Edenius et al 2010). They also indicate that early, long-term investments in the registry enabled innovations and meaningful uses of data that were not initially foreseen (Ovretveit et al 2013). A recent study of European research registries, conducted from an actor-network theory and science and technology studies perspective, characterize these registries as deeply tangled endeavours that span several organizational boundaries and transgress the different institutional ecologies of clinical care and clinical research (Helgesson & Johansson Krafve 2015a). Rather than being built on shared values, these endeavours are held together by diverse, partially overlapping coordinating activities enacting a variety of different values – that also entail friction (Helgesson & Johansson Krafve 2015b).

Finally, some research investigates the evolving system of quality registries in Sweden and explores topics such as auditing, transparency, and quality control in healthcare. An early study depicts the system as a case of mutual resource dependence between the state and the medical profession (Garpenby 1999). Later studies examine the increasing use of registries to monitor professional practice and characterize the result as a loss of professional autonomy (Bejerot & Hasselbladh 2011) or, according to a different interpretation, a new type of 'soft autonomy' that combines external scrutiny with maintained professional control over evaluation criteria (Levay & Waks 2009). A recent study based on actor-network theory recounts the process of how an initially small number of registries for applied research attracted more and more actors with various purposes and grew into an unstoppable macro-actor that speaks and acts on behalf of the incorporated micro actors, including medical professionals (Funck 2015).

Future research avenues

Based both on findings and gaps in previous research, I propose that quality registries can fruitfully be conceived of and investigated as organizational phenomena. Social scientists could make a contribution by considering how general social and organizational theory might be applied to the management and governance of registries. A first step to better understand quality registries in organizational terms would be to conduct comparative case studies of both successful and failed registries, in contrast to previous descriptions of registries in the field of medical science, which tend to focus on successful cases. When analysing similarities and differences between registries, future research could apply a range of concepts and models from management theory and related fields, such as strategy, marketing, and knowledge management, to generate useful recommendations for those who are in charge of quality registries. Theories of knowledge management, for example, highlight the importance of networks, boundary-spanners, and communities of practice in sustaining interorganizational knowledge sharing and development (Edenius et al 2010; Newell et al 2009).

For a more comprehensive understanding of registries as organized eHealth, it would be germane to apply a perspective inspired by actor-network theory and science and technology studies (Latour 2005; Funck 2015; Helgesson and Johansson Krafve 2015a, 2015b). This ethnographic research approach eschews conventional divisions between material and social matters and instead sets out to trace empirically how different kinds of elements – humans, material objects, technical devices, animals, inscriptions, etc. – become associated into more or less durable networks. In the process, new connections are created and others are cut off; new actions are made possible and others more difficult or impossible. It is not just humans that act but also non-humans, and all elements are equally displaced and transformed. Strange as these ideas may seem at first, they fit remarkably well with digital and online events and occurrences. Material objects such as smartphones and other devices connected through the Internet are clearly not just passive things – they perform some sort of action, thanks to the wider web they are part of. In this vein, Lupton (2016) proposes critical studies of eHealth that investigate how humans become interacting nodes in new assemblages of software, smart devices, and 'lively' digital data that contain information about and affect human lives.

From such a perspective, clinical quality registries would be studied as evolving assemblages of humans, digital data points, and other elements. As an illustrative example, we can briefly consider a quality registry for hip replacement surgery (see for example Malchau et al 2002). This is a good place to start, since the procedure of total hip replacement involves implantation of medical devices whose effects need to be monitored closely and in the long term; such monitoring is difficult to achieve without a multi-institutional registry. Those who set up such a registry need to enroll a diverse set of entities – surgeons, implants, patients, data points, regulators, etc – and assemble them all into a durable network. Once enrolled, each entity is potentially transformed by the network as a whole. For instance, an orthopaedic implant type captured through data points in a registry is not just incorporated into a number of patients but also into a wider system of control in which it can be tracked, scrutinized, and put to trial.

In addition to describing failed and successful attempts to form such actor-networks, future research should explore how stabilized registries affect the human actors involved. Questions that deserve attention include: What actions by clinicians, patients, and other actors are enabled or disabled by a quality registry? How are clinicians, patients, and other actors thus transformed? Who is the patient in a quality registry? By asking such questions, future research would stimulate deepened and critical reflection on clinical quality registries as eHealth.

eHealth, a lure or cure for mental health?

Sigrid Stjernswärd

Estimations show that within a given year, 27 to 38.2 per cent of the EU population risk developing a mental disorder (Wittchen & Jacobi 2005; Wittchen et al 2011). This represents an increasing burden and source of distress for patients and their families. Mental disorders affect cognitive, affective and behavioural processes negatively, with detrimental effects on quality of life and the ability to function in daily life in private, social and professional roles. In addition to increasing frequencies of chronic conditions, including mental illness, and an ageing population with complex healthcare needs, a challenging burden is also associated with high levels of immigration and associated trauma, with subsequent mental health repercussions. There are wide global disparities in access to mental healthcare and numerous challenges related to areas such as governance, resources, competence and mental health literacy (WHO Atlas 2015). Together with limited resources, these factors represent a challenge that calls for novel and cost-effective ways of addressing future healthcare needs.

The new technological trends are revolutionizing citizens' attitudes and expectations towards healthcare. The trend is towards consumer and data-driven care and more responsibility and active participation in one's own healthcare (Patrick 2016). This goes in line with the advocated principles of participation and self-determination in mental care (Socialstyrelsen, 2011a; Socialstyrelsen, 2011b). However, we need to examine what such trends really mean for patient empowerment and how eHealth solutions can address individual needs, without risking the exclusion of those in greatest need of care and support. The development of eHealth opens up for great opportunities (such as more prevention and cost-effective care), but also potential negative and at worst fatal effects (such as misinformation or treatment delay) that need to be pondered. Various stakeholders with differing motives lie behind the development of eHealth solutions, not least those with commercial interests.

The future encompasses a variety of mobile apps and devices (from wellness apps to purely clinical applications) that will allow general consumers of health products/services and patients to monitor their own health and share data with others, such as family, physicians, laboratories and others. This represents a potential to enhance mental healthcare processes, going from prevention and diagnosis to treatment and follow-up. Essential prerequisites to attain effective and sustainable care processes and health outcomes are that users are capable and motivated to engage with and adhere to eHealth interventions, not least in regards to the functional impairments attached to mental disorders. We need a proper understanding of how to use and research eHealth solutions in the field of mental health. This requires competence from a diversity of professions and disciplines and the development of suitable research designs, with careful consideration of ethical aspects and usability. Thus, involving, educating and supporting end-users, be they general consumers, patients, health professionals or future generations of researchers, is vital.

Stigma attached to mental disorders and insufficient resources are common barriers to treatment (World Health Organization 2001) as are transportation and fatigue, which can impede help-seeking. eHealth interventions that can be carried out at a time and location of one's choice may help overcome such barriers. Sweden is a highly Internet-connected nation and the major breakthrough of recent years implies an increased use of mobile Internet in terms of number of users and frequency and duration of use, also among youth (Findahl 2011). The latter comprise a risk group with high frequencies of mental illness. Social media represent another potential venue to reach at-risk groups. Innovative eHealth solutions may facilitate individual home-care in the areas of mental health, access to and continuity of care, and advice/support to patients and caregivers (Vinnova 2014), all of which are central to good care.

Australia is far ahead with government-led initiatives and implementation of a national eHealth strategy and mental health solutions, but the Netherlands and Sweden are also at the forefront in terms of eHealth. An example is the intensive research activity on cognitive behavioural therapy online, which has also been implemented within the regular healthcare system in parts of Sweden (see for example Linderfors & Andersson 2016). The digitalization of health nevertheless means that consumers and patients can access information and services from multiple, more or less serious

actors on a global level, with all the subsequent challenges that this entails in terms of trustworthiness, quality, regulatory matters and ethical issues, to name a few.

eHealth and mental health issues – what do we know?

Miscellaneous computer-based and mobile-based eHealth initiatives have been found to contribute to enhanced care processes and health outcomes in the area of mental health. Computer-based interventions including monitoring, therapy and/or psychoeducational elements have demonstrated good acceptance, efficacy and cost effectiveness for a diversity of mental health conditions (see Cunningham et al 2014; Harrison et al 2011; Griffiths Farrer & Christensen 2007). Yet further research is needed to investigate individualized (in terms of usability, affordability, intensity, format, and other user requirements) and blended format interventions (such as online/face-to-face, interventions with diverse underlying theoretical models).

Machines may heighten the accuracy and efficacy of clinical assessments, facilitating early prevention and better care of mental disorders (Gratch et al 2014). Online initiatives can also be useful for educational and networking purposes for health professionals. Further examples of valuable online initiatives are support groups and psychoeducation aimed at patients with a mental health condition and their families, with the potential to contribute to empowerment through increased knowledge, social support and improved health outcomes for patients and relatives. Such interventions can help overcome the stigma that can impede help-seeking, not least through the experienced benefits of anonymity online.

Social media have also been used in connection with anti-stigma campaigns in several countries, with the ambition to improve the public's knowledge and attitudes towards mental health and functional disabilities (see for example Evans-Lacko et al 2013). Further research is needed to investigate the appropriateness and efficacy of diverse online interventions designed to address the burdens of mental illness while addressing the affected stakeholders' interests – to see what works for whom, why, how and when.

In parallel with computer-based interventions, mobile health (or mHealth) represents a unique opportunity to address mental health issues

in innovative ways. It encompasses mobile phone applications but also sensors, wearables and mobile devices for decision processes, access to and provision of health services, and management of daily activities (Varshney 2014). The combination of communication and hardware functionalities will contribute to moving the treatment process even further outside of care (Price et al 2014). It can facilitate the delivery of just-in-time interventions and the promotion of clinical goals at times when support is most needed (Turvey & Roberts 2015), representing a valuable asset in the handling of mental disorders. Mobile phones have the potential to address the digital divide associated with web-based interventions and reach out to otherwise difficult-to-access groups, since its proliferation among populations of all sociodemographic backgrounds is widespread.

Affordability of eHealth services is essential, especially considering the detrimental economic consequences subsequent to health afflictions, not least for individuals with severe mental illness. Mobile phones are easy to carry and location independent, allowing the collection of personal data (such as experience, behaviours) in real time and in the subjects' current environment (Harrison & Goozee 2014). This opens up for improved care processes (including appointment show-ups, speed of diagnosis and treatment, teaching and training) and outcomes (such as pharmacological compliance, symptoms, behaviour change and self-efficacy) (Krishna et al 2009), but also for novel research opportunities. Mobile apps have the potential to facilitate increased access to and use of evidence-based care, better inform and engage patients, and enhance care after formal treatment with the potential to sustain treatment gains (Price et al 2014); all these represent essential aspects in managing chronic conditions and preventing relapse. Research is needed, however, to verify this potential and patients' willingness to engage with such solutions, not least in respect to integrity and safety. Diverse apps related to mental health appear on the market every day, but most lack theoretical foundations and proof of concept as to their efficacy; which is another area for further investigation. Consumers, whether patients or health professionals, also need help to locate suitable, trustworthy and effective apps with true potential to promote mental health outcomes.

Concluding thoughts and future research

We can't know for sure how the paradigm shift ensuing from the current technological development will affect mental healthcare and the expectations and behaviours of patients and health professionals. Nevertheless, the diversity of stakeholders and rapid development of eHealth demand that we address a range of challenges, including research-related ones. We need further research with appropriate designs to investigate the potential of eHealth to enhance care processes and mental health outcomes (long and short term). Such research should examine diverse populations (in terms of age, diagnosis, cultural background, etc.), with evidence-based interventions that can be tailored to address individual and complex care needs. Studies of the potential negative effects of eHealth in the area of mental ill health are essential to understand potential risks and shortcomings. We need implementation studies with the identification of facilitators and barriers to eHealth adoption and dissemination, but also policy-focused research. The enhanced technological possibilities to collect information and improve and tailor interventions, and the research potential associated with big data require cooperation across disciplines and new ways of thinking within mental care, even though this potential raises a number of ethical questions.

Sigrid Stjernswärd at eHealth seminar.

eHealth and the digital reinvention of healthcare

Martin Stridh

The aim of this text is to discuss the rapidly approaching meeting between the tax-funded healthcare system in Sweden and the health-related initiatives of the private sector. Important questions are how the healthcare system can adapt to and make use of the initiatives in the private sector and how personal initiatives can be embraced and integrated into a future primary care system.

The world has changed

Less than ten years ago, most measurement systems were built from scratch or from available hardware parts, with all aspects – including sensors, data storage, data analysis and user interfaces – integrated into one system. With the introduction of smartphones, apps and cloud services, a sensor and an app are sufficient for most applications. The use of existing personal infrastructure such as smartphones and Internet infrastructure such as cloud services in products and systems has completely changed the way technical systems are being built. Data can be recorded at one place, stored at another place, analysed at a third place, presented to a user at a fourth place, and shared with others at many other places. Following this development, we are now facing a change of the entire diagnostics sector where many previously complicated procedures performed by healthcare professionals within the healthcare system will soon be simple, in-home tests.

This will likely challenge the tax-funded healthcare system in many ways. Contrary to today when access to diagnostics at different levels is controlled by nurses and doctors, diagnostics will be available for anyone whenever and how often they want to as long as the tests are harmless. For those who want to know more about their health status it will certainly be possible without going to the doctor.

This development raises many questions. How can peoples' own initiatives work together with the present healthcare system? How can the healthcare system adapt to the fact that parts of the diagnostics sector are moving beyond the perimeter of the healthcare system? Who will pay for diagnostics, screening, risk assessment and prevention when their access is not controlled? Is there a risk that healthcare is being reinvented outside the traditional healthcare system in Sweden? And, what does this mean in terms of citizens' equal rights to healthcare? This development will not stop with diagnostics. Already there are numerous initiatives on the private market aiming at both treatment and rehabilition.

The healthcare system is transforming

Once a very closed sector, the system is now hallmarked by guidelines for how to CE-mark standalone software with a medical purpose, including apps and different types of medical information systems, and there are clear definitions of when a smartphone or tablet becomes a medical device [1]. In the past few years wireless networks have become frequently used for many purposes within the healthcare system [2]. Improved data liquidity and more modern and user-friendly administrative tools have been set as important long-term goals for the healthcare system on a governmental level. Under the umbrella *Mina Vårdkontakter*, a modern way for citizens to communicate with the healthcare system has been introduced where citizens can electronically manage tasks related to visits, prescriptions, medical records etc (see Linholm & Erlingsdóttir, chapter 8).

Another recent national initiative is a portal where all citizens can store and monitor health-related data that they have recorded on their own initiative; this is called *Hälsa för mig* (see chapter 2 in this White paper). This stored data and information is owned by the individual user in a similar fashion as money in a bank account and the system is open to third-party products and services for data collection, analysis and aggregation. Data from the healthcare system may also be imported. This is a platform on which both private companies and other actors can place apps of different kinds. Some important aspects of this system are that the user owns his or her data and can decide what to do with it, and that it is a controlled area for private initiatives.

Healthcare inherits business model from the IT sector

We presently see major initiatives from the private sector in the development of various e-health solutions. A major challenge for the industry, however, is to find sustainable business models for these products and services. Both apps and external sensors are often cheap, which means that volume becomes important. Monthly subscription fees may be possible but require a relatively large delivered value every month. Indirect payments with user data or exposure to commercials are two commonly used strategies in the IT sector and we will probably see more of these in the healthcare sector. The key behind practically all significant Internet applications is that they are backed by a unique and specialized database often based on user-generated data [5]. However, payment with user data is more controversial for healthcare than for many other areas. When it comes to business models in general, a short "distance" between the one who pays and the one who benefits from the investment is attractive, while the opposite is complicated. This is particularly complex for the healthcare sector since investments in such activities as prevention may pay off in a different place far away within or even outside the healthcare system. The complexity increases further when a part of the system is tax-funded.

Many roads ahead, but which one to choose?

The following text is not a proposal for a future primary care system but is rather an attempt to raise questions about which ingredients a future primary care system may contain. A null alternative for the future is to not strategically integrate the initiatives of the private sector into the tax-funded healthcare system, and just let citizens, primary care units and hospitals buy systems and services from the private sector when they need them. There are, however, several difficulties with such an approach: data ownership may be spread out; the approach relies on doctors and nurses in the primary care system understanding the technical systems and being able to make use of their results. It is unclear how personal initiatives will lead to access to advanced healthcare without going via the traditional primary care system; it is also unclear how the burden generated by personal initiatives can be managed by the primary care units. Another difficulty is that the speed of health IT development is approaching the speed of IT development.

HealthKit and CareKit from Apple are examples of this development. For today's primary care units, it will be a challenge to keep up with this pace.

As an alternative scenario, assume that in the near future, in addition to an advanced healthcare system, i.e., today's hospitals, there are numerous health-related systems and services available for citizens to buy. Some are similar to today's primary care services while others are home-based screening, prevention, and monitoring services for different diseases. Yet others are related to genetics and lifestyle risks. There are so many alternative services for every possible disease that people will have a hard time selecting them and knowing which are good. Therefore, there are companies or health providers putting together useful systems and services into more understandable health subscriptions. In order for the healthcare system to be able to make use of the results of all the services without needing to redo all tests, we can assume that somewhere there will be a list of approved and reliable systems and services that generate acceptable burden-to-benefit ratios from which health providers can choose.

Let us further assume that the healthcare system pays for a basic health subscription for all citizens to assure equal access to diagnostics, that the price is fixed at a rather low level, and further that the health providers compete to provide the most prevention and diagnostics for this amount. They can also provide add-on services outside the tax-funded basic subscription. Thus, there is a private market for services and a private market for health providers.

In order to control the health provider market, it is regulated so that just a small number of companies are licensed to be health providers with the right to place burdens on the advanced healthcare system. Now, the healthcare system wants the health providers to have three important roles: 1) to be the gatekeepers for advanced care, i.e., to allow and embrace all types of personal diagnostics but internally handle all requests that do not require advanced care, 2) to have the goal to prevent diseases and detect diseases as early as possible before they become serious and thereby burdens on the advanced healthcare system, and 3) to make sure that all citizens' health data is collected back into the healthcare system/personal health accounts. In order to achieve this, healthcare providers, in addition to receiving subscriptions fees, are reimbursed based on documented health improvements of individual citizens and early detection of problems that otherwise would place a larger burden on the advanced healthcare system or society.

Based on such a scenario, it may be interesting to list a number of possible consequences:

- *People can use any diagnostic tool they want.* The health provider accepts data from a large number of tools within and outside the basic subscription. People select the provider that offers the best service. The health provider is the gatekeeper to advanced healthcare and drug prescriptions.
- *People do not need to be experts on specific technology or select companies from which to buy specific services.* They use the supported solutions within their subscription.
- *The goals of the health providers and those of the entire healthcare system coincide.* The health providers compete to keep as many of their registered citizens as possible healthy and out of advance healthcare, with a clear goal to optimize every individual's health status. Each health provider develops their own competitive strategy using the latest technology. Thus, the diagnostic sector will progress at a speed more similar to that of the IT sector.
- *There are well-defined markets for both services and health providers* with a symbiotic relationship between the healthcare system and the health, service and technology providers and high competition at every service level in the system.
- *Health data is still owned by the citizens and is easily integrated into the healthcare system.*

There may also be many other consequences and many other possible scenarios for how the tax-funded healthcare system and the initiatives of the private sector can converge. The main point of this discussion is that a well-informed strategic discussion about the desired way forward is needed, since all different roads ahead have consequences that may challenge both the entire legal framework of the healthcare system and our view of equal healthcare (see Mattsson, chapter 3). Interestingly, there are many possibilities for the *Hälsa för mig* platform to play several different roles in this development.

Data, knowledge, and the wisdom of the crowds

Another component of e-health that will likely expand significantly over the coming decade is related to different types of data and knowledge. New *clinical knowledge* is published continuously and knowledge contained in *electronic medical records and national quality registers* (see Levay, chapter 10) is growing rapidly, without a fair chance for the individual doctor to keep up with this growing knowledge. Other sources of clinically relevant data are *patient measurement data* stored at hospitals, e.g, ECGs measured over decades, *citizen health data* that will soon be stored in personal health accounts, and *patient experience data* which presently is not collected but may be entered into social networks similar to Patientslikeme.com. Clinical decision support systems that can take all this information into account and that can match everything we know about diseases and treatments to everything we know about a patient are urgently needed. Presently, IBM Watson is an example of such clinical decision support system under test [4]. Many future patients will probably expect the best available knowledge in the world when being treated for serious diseases.

Administrative health data is yet another source of information which, if opened to third-party developers, would open up for generations of health maps, dashboards, trends, comparisons between units, regions, and countries, etc for use by everyone from politicians and decision makers in the healthcare sector to patients in need of help or private corporations such as insurance companies.

Related to this area is the Healthy City concept [6] where *personal health, population health, and environmental health data* meet and where typically third-party developers can also combine information into web-based health tools, creating insight into where it could be good to live or exercise, where it is better to have asthma or heart problems, and where it is best to be treated for a certain disease, thus creating incentives for other places to work towards the same status. A Health City can include everything from walkability, to access to good food, to physical recreation and clean air.

For the future, it is important to identify all types of data sources and think about how they can be used to create accessible and useful knowledge within the healthcare system, for decision-makers and the public. As for primary care, it is important to consider the ways in the momentum of the private sector can be used to accelerate progress within the healthcare system.

Summary

This text is aimed at discussing how the future healthcare system can work efficiently together with the private sector to optimize future health. There are several possible roads ahead and the main point of this text is that since the world is rapidly changing, there are important consequences – both when moving into the future without making structural changes, and when making radical changes to the healthcare system structure. Significant research efforts are urgently needed to explore and evaluate different possible scenarios.

Working at the institute. In sofa: Cecilia Lindholm, Gudbjörg Erlingsdóttir and Jonas Borell. Standing: Charlotte Levay, Helena Sandberg, Charlotte Magnusson and Mats Johansson.

Epilogue

The different reflections and discussions in this White Paper are the research group's final contribution to the work at the Pufendorf Institute. At the same time, the White Paper can be seen as the starting point for the continuation of the eHealth theme in form of the new research network, eHealth@LU.

The time at the Pufendorf Institute during 2015–2016 has given us the opportunity to gain insight not only into eHealth, but also into each other's research fields and how they can make a combined contribution to broader and deeper knowledge and understanding of this complex social and technological phenomenon.

We now understand more about the opportunities and challenges that accompany eHealth development and implementation, but we are also aware that most of the work lies ahead. The eHealth area is growing; there are numerous studies that need to be done and that can be supported by this multidisciplinary network. Apart from the twelve researchers in the core group, the network encompasses around thirty experts, including both junior and senior researchers as well as practitioners. Therefore, we look forward with great enthusiasm to future research endeavours and collaboration in the eHealth@LU network.

Gudbjörg Erlingsdóttir & Helena Sandberg

Lund, May 15, 2016

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Links in chapter 12, Martin Stridh:

[1] https://lakemedelsverket.se/upload/eng-mpa-se/vagledningar_eng/medical-information-system-guideline.pdf

[2] http://www.ascom.se/sw/index-se/

[3] http://www.oreilly.com/pub/a/web2/archive/what-is-web-20.html?page=3

[4] http://medrio.com/partners/ibms-watson-and-the-future-of-healthcare-infographic/

[6] http://www.healthycity.org

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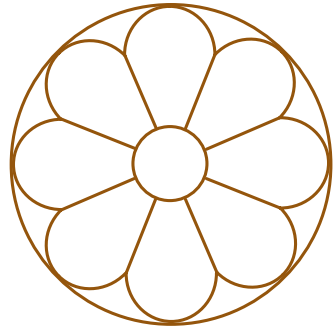

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