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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.