19 Key Essays on
How Internet is Changing our Lives

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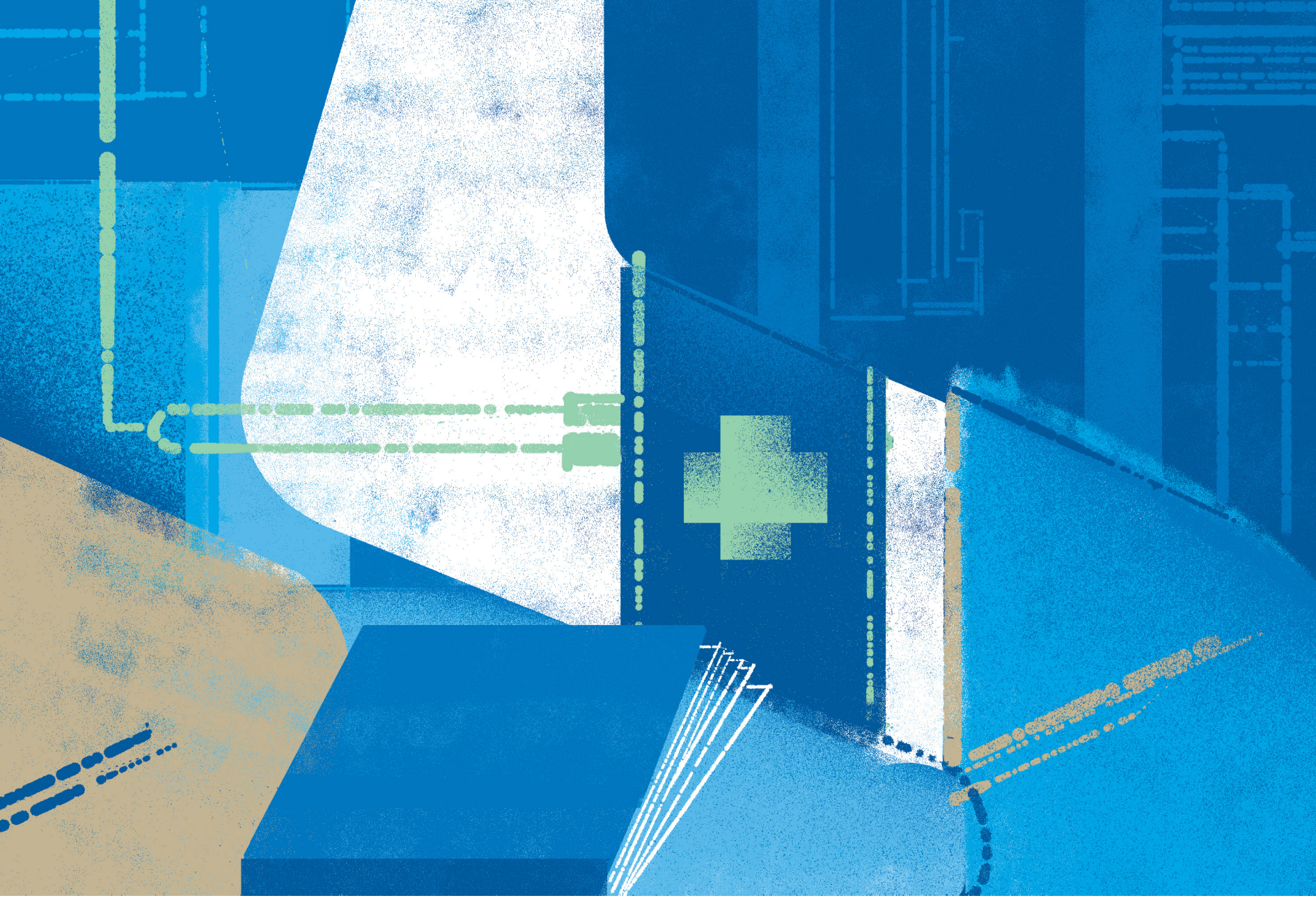

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The Way of the Dodo

"The Internet has revolutionized our lives!" is an often heard exclamation. The Internet has added a lot to our lives indeed, and has also made a few things disappear. Think of all the things that became obsolete due to the Internet, such as letter writing, privacy, and all kinds of brokers and middlemen.

These developments make me think about the dodo, the notorious one-meter-tall, pigeon-like, flightless bird, last spotted by a Dutch mariner in 1662 near Mauritius. Of all the species that became extinct, the dodo has become a kind of metaphor for extinction. To "go the way of the dodo" means that something is destined to go out of existence. In this era of Internet and technology, this goes not only for flora and fauna, but also for stuff we use or things we do. Many futurists have already predicted that things like post offices, taxi drivers, manual labor, and even death itself will go the way of the dodo.

So what about healthcare? What will vanish in the field of medicine? Will technology and the Internet take over like they did in the music and travel industries? Will nurses be replaced by robots? Will the doctor be replaced by a smartphone app? Will we no longer go to a hospital or to the doctor's office? A shift is surely occurring, and some things in healthcare have already began their march on the way of the dodo. But, in my opinion, we will still need medical professionals. Real people with real compassion giving great care.

The challenges that healthcare faces are huge; that is no breaking news. Financial mismatches, doubling of healthcare demand, and the shortage of skilled personnel (the Netherlands will lack 400,000 professionals by 2040) will drive healthcare systems to *reinvent themselves*. Moreover, there are two developments awaiting *at the gate* to disrupt many of the current care models: the assertive patient is here to stay, and new technologies are developing at exponential rates. The impact of new communication paradigms, such as social media and transparency of performance, is just as underrated as is the role of e-health overrated. Medical professionals need to think big, act small, dare to fail, stop talking... and start acting NOW.

If medical professionals still want to be a relevant cog in the healthcare system in, let's say the next five years, they should be concentrating on these three topics, for themselves, for their institutions, and most of all for their patients:

1. Engaging patients
2. Exponentially growing technology, including the Internet
3. Social media

I will now address a selection of future healthcare dodos. With the power of the three topics above, the Radboud REshape & Innovation Center has initiated a range of innovations. Among these are (in random order):

- HereIsMyData™—A service that consists of a Personal Health Record, a community aspect, and an eHealth connector.

- AED4US—As of 2009 we are crowdsourcing the locations of automatic electronic defibrillators (AEDs) in the Netherlands. The program currently has the largest database in the world, with over 18,500 units and nearly 300,000 downloads, and benefits from the assistance of the public.

- FaceTalk—A videoconference system we've developed that allows health-care professionals to consult with patients and colleagues in an easy and secure way without additional hardware other than regular computers or tablet PCs.

- AYA4—An online community for young adult cancer patients (18–35 years of age) to share, in a secure fashion, intimate details about their life with cancer, about challenges such as relationship, work, finances, etc. Enrollment currently has a national reach.

- TEDxMaastricht, TEDxNijmegen—Every year we hold a high-level conference—twice in Maastricht (2011 and 2012) and twice in Nijmegen (2012 and 2013)—to share ideas, dreams, and examples; that is, over the Internet. For 2014 we are organizing 360andabove,[1] a conference that will run virtually on the Internet, connecting patient-centered innovations

1. http://www.linkedin.com/today/post/article/ 20130908153807-19886490-the-24-hours-of-health?

in a new format. For 24 hours in a row, starting in Nijmegen, traveling with the daylight one time zone at a time. From Nijmegen to London, the East Coast and Midwest U.S., California, Canada, Australia, Japan, India, Hungary, France, and back to Nijmegen for the finale.

With these projects we try to outsmart the dodo; otherwise we will become living (or extinct) examples in the near future for others that do indeed innovate in a way that creates *futureproof* health (care).

Location

One of the major shifts in healthcare is that location is becoming less important. Due to new (mobile) technology and cheaper testing methods, things are already changing. And yet, rising healthcare costs are forcing all stakeholders to become much more efficient with regards to processes, staff, and overhead. The number of mergers and takeovers is increasing. Whether or not that is the way to go is still to be seen. We at the Radboud University Nijmegen Medical Center think there are other ways to become more efficient. For example, by creating a network based on collaboration instead. With different points of care nearby, and with the help of new technology, a great of number of things can be achieved. We will be able to monitor our patients at locations just around the corner, or even in their own homes. More specialist procedures will be performed farther away. Over the past decades we have tended to take healthcare away from the people themselves. This started with bringing people into hospitals rather than caring for them in their homes. Healthcare has become centralized in institutions rather than in networks, as it was in the old days. But new technology is enabling us to reverse that while keeping the same high standards. So, this means that trusted, well-known hospitals with doctors we are now so familiar with will increasingly disappear. On the other hand, we will bring health(care) back into people's homes.

Duration of the Stay

A decade ago, some procedures required up to 15 days of hospitalization. Now, they take 3 days. This is due to new technologies, innovations in medicines, logistics, and protocols, and new insights on rehabilitation. A median stay in U.S. hospitals at present is about 5 days. Long stays for regular procedures will become unnecessary, and prohibitively expensive. Monitoring at home, enabled by the Internet, is increasingly assuming an important position in this field.

Individual, Unorganized Healthcare Professionals

Healthcare is becoming even more complex than it already was. This is caused by increasing legislation and severe budget cuts.

There are many constraints on medical education and the overload of information that has to be digested makes it hard to keep up. In addition, the administrative burden is increasingly distracting medical personal from delivering actual healthcare. The part-time ratio for healthcare workers is increasing. The number of female professionals entering healthcare adds to this tendency (Graham 2012). More and more tasks are delegated from doctors to nurse practitioners and physicians' assistants; next up is *delegating* to the patients and their network. In order to maintain quality standards and to be able to keep collaborating on complex issues, working in groups or setting up strategic partnerships could benefit healthcare processes.

I believe that within one or two decades, individual, unorganized healthcare professionals will become a minority.

Two-Party Research in a Three-Party World

Up until now, health research has mainly been done by the pharmaceutical industry and researchers. Patients were merely a passive object. I often

say, “Doing (as in designing) medical research without the cooperation of patients is like racing a car backwards... blindfolded.” Now, we have the tools at hand to involve patients. New communication techniques have democratized the media, and we have even seen regimes forced from power through revolutions—and the role of the Internet was crucial. The same tools will also be employed to organize patients around research on matters they care deeply about, namely their own health or the health of a family member. Research with patients in co-control will transform traditional research and create a pathway for (applied) research through new systems that will change the situation forever. It will just be a matter of time before these kinds of tools will become available to patients. We hope to contribute to this goal with MedCrowdFund™, a social platform (like a medical Kickstarter) where patients can design and find funding for innovation and research. Let’s see how long it takes for a two-party health research system to be transformed into a three-party one. Patients will swap roles: they will go from being the object, to being the subject, to acting as a partner in research. A very good example is my friend Jack Andraka, born in 1997(!). After countless rejections by traditional institutions, and with a lot of perseverance, Jack developed a pancreatic cancer test “just by using Google and Wikipedia.” It is designed as an early detection test to determine whether or not a patient has early-stage pancreatic cancer. The test is over 90 percent accurate, and is 168 times faster, 26,000 times less expensive (costing around $0.03), and over 400 times more sensitive than the current diagnostic tests, and takes only five minutes to perform. He says that the test is also effective for detecting ovarian and lung cancer, due to the same biomarker they all have in common. Truly inspiring! So medical professionals must look carefully at these new initiatives; they need to judge them not on *what* they are doing, but on *why* and *how*. They need to reach out, explore, and challenge diseases together!

Being a Good Doctor Won’t Be Good Enough Anymore

We have gotten used to submitting and finding customer opinions on almost every kind of service online. Reviews and ratings of tourist hotspots, travel agencies, restaurants, financial products, and so on are now in the public sphere. And of course, healthcare professionals are part of this trend.

A treatment has become an experience, and the customer's satisfaction with it in general might become equally important as the quality of the medicine practiced.

According to Pew Research, 50 percent of smartphone users in the U.S. use their device to look up health information; a recent study for the Netherlands showed that this figure was 60 percent. This means that they will probably have researched their physician online while they were sitting in the waiting room, and that they will review him or her as soon as they have left the building. "Hospital-ity" has regained its vital meaning.

Not only text-based web content, but also informational videos will become increasingly important. Healthcare could benefit from adopting the use of video as well. It offers great opportunities for providers to present themselves and their services.

A caveat! The quality of strictly medical care will no longer be the only indicator people compare in order to choose healthcare providers.

The Patient Is Not in the Middle

Many healthcare providers are pivoting their service by putting the patient in the middle, in their ambition to change healthcare into a more open, co-creative environment. Putting patients in the center, however, seems to me to be one of the most paternalistic approaches a patient might have to deal with. Patients are not objects around which healthcare providers perform their duty. Patients should be(come) partners. They are equals in the team that collaborates to sustain or achieve their optimal health.

If patients want to take control of their health but are unable to, we must teach them. If they want to but can not because there is no system or technology, we must build it for and with them.

And if they do not want to, we must deliver healthcare in the traditional way.

In the center, however, is something else: it is an ear. A very important organ (that's why we have two, right?)—it is the sense of hearing that many healthcare systems have stopped using. As healthcare professionals know what's best for patients—at least that's what they think—they make choices *on behalf of* instead of *with* the patient and their families.

We often grab at *innovation* as the big solution for everything. We start innovating without having looked closely at existing procedures and at how optimizing these existing systems could bring great benefit and improvement. That (at least in my opinion) starts with really listening to what is truly needed. Healthcare providers need to stop assuming, they need quit thinking they "know" what patients need; or from a industry perspective, what healthcare professionals need. Listening is asking. I highly recommend appointing a CLO into every healthcare team; I created and appointed this position back in 2009: a Chief Listening Officer. Employed both online and offline, every time we intend to change our healthcare delivery the CLO will interview patients, family members, and informal caregivers: "How can we help you?" Not being a healthcare professional like a doctor or nurse, it appeared that patients were more open to the CLO, and more candid than with the focus groups, surveys, etc. we have used until now. Every project we kick off begins with the CLO listening to what the target groups really want. In almost every project that we have run the original plan our colleagues came up with changed, and through that process of adaptation benefitted significantly.

Partnerships

One should not underestimate the power of collaboration. At our medical center, we love to team up with other parties, nationally as well as internationally. It is imperative that healthcare providers do not suffer from the not-invented-here syndrome. They need to open up, and unlock the gates surrounding their domains. It is hard to find likeminded collaborators, but they are out there! In the Netherlands we mostly come across the usual suspects, and thus we broadened our horizons and contacted numerous international innovators. In other countries one finds different cultures and mentalities. We are impressed by the pace we are able to

maintain in our international teams, and a bit ashamed that it is quite clearly impossible to develop and implement quickly in our own country. The importance of the Internet in this respect is also crucial. Connections are being made through social media, based on slideshows we have put online, with people often reflecting on photos we have published in social media of the things we are doing. Entrepreneurship, leadership, decisive action, and speed are important assets for implementing innovations successfully. Without them, one cannot evolve. And the fate of the dodo is one step closer.

Rules and Regulations

The thing with exponential developments is that they take little time to develop, but more time for laws and ethics to catch up. How should the regulatory agencies prepare for an ever-changing world in which technology is growing exponentially and changing the arena? In the *old* days, it took big companies years of innovation before they could launch a new medical device. Nowadays, with the time to market dramatically shorter, new devices are released on a daily basis. Does this actually change the way regulatory agencies should act? In the Netherlands, regulatory requirements for digital healthcare innovations are hot at the moment; it is at the center of attention of the Dutch Health Care Inspectorate. And that's a good thing. The certification of medical applications will contribute to a rise in quality. I do not think, however, that this is enough. I strongly believe that the appliance of open technical standards, such as for information exchange and the reuse of existing and proven applications, should be made mandatory by policy makers. The software industry has powerful interests. They operate defensively and are far from eager to open up their systems and thereby implicitly grant access to competition.

Furthermore, the financial system must be improved. If financial compensation does not end up in the tills of the developers and producers of (digital) healthcare innovations, the dodo will soon be joined by many talented peers.

e-Go Systems

At the moment, huge amounts of data are being generated by information systems, medical records, tracking devices, lab results, image resources, etc. What we need is the ability to mine these different types of data and be able to understand their meaning, the relation between them, and how they interact. We need a central repository where anyone (not only patients, but any citizen) can access their own data in a comprehensive way—not only health data, but also other kinds, such as financial data. The patient (or citizen) must be able to decide with whom to share it. A patient could share data with his physician or siblings, so that they may both use it on relevant occasions. The reality is that almost all healthcare information systems are focused on the healthcare professional. It is not an open system, but closed, with data stored in hidden silos. It is usually very unattractive and the user experience is poor. I call these *e-Go systems*. They are egoistic, hierarchical systems that do match up with contemporary demand, and mostly do not connect to other systems in the healthcare chain outside of their own. They somehow still manage to profit from business models that have already failed in other markets. These systems should have gone the way of the dodo a long time ago, but still manage to survive, as yet.

We have to work on open, transparent, user-friendly, and cooperative systems based on open technology standards that actively promote interoperability. We have to move on from e-Go systems to e-Co systems. Now is the time for an e-Co system that sees and treats the patient as the linchpin: a system that is the constant factor in any health-related action and intervention; a transparent system that services patients and their networks independently. Putting people in charge of their own personal health data, of course, also creates co-responsibility. I believe—and have also witnessed it—that a lot of people are able to and want to be in that position. Giving patients control over their own data is an important step in making patients partners.

Here Is Your Data!

This is exactly the reason why we at the Radboud REshape & Innovation Center decided to start a *noncommercial* service to boost the process of

creating these e-Co systems, setting them up, validating them through scientific research, and making them widely available. Just like our other tools—FaceTalk™,[2] MedCrowdFund™ (e-Patient Dave 2012),[3] our AYA4-community (Tucker 2012), and AED4US (Root 2012)—we sometimes set up services or products ourselves if we think the market acts too slow or at too high a price. We recently announced an e-Co system HereIsMyData™.[4]

HereIsMyData™ consists of:

1. a Personal Health Record;
2. a community system that gives patients, caregivers, and families the opportunity to talk about a specific disease;
3. and connectivity tools for many kinds of personal health devices like Withings,[5] Fitbit,[6] Jawbone-Up,[7] Scout,[8] etc., and great data visualization tools. Of course, we'll connect our FaceTalk™ and MedCrowdFund™ to it.

So it is not a platform; it is more like a service combining the best of three worlds. This service will give people the power to combine a lot of their personal health (measurement) data in one place. If this data is needed for one's health(care), it also can be used in one's own Personal Health Record (PHR). How it differs from a great many platforms and systems is that with HereIsMyData™ people decide for themselves who is granted access and subscription to their data. In addition, it is possible for a healthcare professional to subscribe to connected services of patients, such as scales and other barometers of clinical measurements; and the other way around, patients can subscribe to data from the hospital, such as blood values or clinical notes (from their electronic medical record [EMR]). In addition, they can grant healthcare professionals like their general practitioner but also family caretakers access to their personal data, for instance their weight history. At the moment, this project is our main spearhead and participation is open to all.

2. http://en.facetalk.nl/
3. http://www.medcrowdfund.org/?_locale=en
4. http://www.hereismydata.com/
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Reshaping Radboud

In almost all of my keynote presentations I emphasize “stop talking, start doing.” And by living up to this mantra we have been able to realize many innovative projects. Inevitably, not all of them were successful, but we always ran a number of projects simultaneously. So quite a few managed to survive evolution (so far). We incubated these projects in our Radboud REshape & Innovation Center, and when they reached adulthood, we let them go—back home, to the Radboud University Nijmegen Medical Center, where they could be implemented and incorporated into regular process flows. Of course we stay in touch, to perform maintenance and to evaluate. And it is very nice to see how these projects have found their way into the daily routine of nurses, physicians, managers, and board members. We collect evidence by researching the effectiveness scientifically and we incorporate our vision, experience, and innovations into the curriculum. So now our innovation flywheel is in perpetual motion. For instance, we discovered that at this moment (Summer 2013) the viewing angle of Google Glass prevents surgeons from using it optimally. We provide the Google Glass team with valuable feedback and at the same time brace ourselves for impact. Because we now receive so many ideas from inspired medical professionals on how to improve their work by using Google Glass. This gives us the opportunity to keep innovating. Because we *will* beat the dodo!

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