

# The healing power of information technology

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## Interview with David Blumenthal, President and CEO, The Commonwealth Fund

**OECD Observer: On the OECD healthcare conference website you paraphrase Donald Berwick: “We are all guests in our patients’ lives”.\* What exactly do you mean by this eloquent phrase?**

David Blumenthal: Don, who is a good friend, has a marvellous way with words and analogies. I practised primary care for 35 years, and my view is that physicians are in many ways the servants of their patients, their advisors, their supporters.

The primary ethical duty of respecting patient autonomy means that it is the patient who calls the tune, using the information and advice that we as doctors provide. I find Don’s analogy to being a “guest in their lives” very apt from that perspective.

If a patient is competent and speaking for him or herself, as long as his or her decision did not affect the population’s health, that patient then has the right to determine what happens to him or her, and to accept or reject my advice.

**In what situations can a patient’s decisions affect the population’s health?**

If you have a communicable disease, which by your behaviour could affect others, such as Ebola, HIV or tuberculosis. There is a very long history of public health activity that’s related to the containment of infectious illness, and in such cases, people are not just acting for themselves. The state in many countries, recognising such cases, empowers the medical profession to move beyond advice to actions that are coercive, in the interest of a larger society.

Also, when parents speak for children, there are limits to their autonomy, and we recognised that recently in the US in respect of the willingness of parents, for example, to forgo chemotherapy for children with cancer or needing blood transfusions.

**Would you say that your experiences regarding patient relationships are unusual or do a lot of physicians share them? Surely in the end, the traditional relationship between a passive patient and doctor as the dominant player still suits many people, doesn’t it?**

I am really describing my attitudes and beliefs, rather than my experiences. I have certainly often had patients who very much want to delegate decision-making to me, patients who say “you’re the doctor, you tell me.” And that’s fine. As long as it is clear that that is what the patient wishes.

Is it a traditional attitude? You know, physicians and other clinicians range across the spectrum in their views. An earlier generation of physicians would have tended to believe that by virtue of their knowledge and their training, they ought to be in charge, people should follow their advice, and that it is a failure of the patient when they don’t. Such attitudes are less prevalent than they were, but they still exist. These attitudes develop in different ways. Sometimes doctors come into training with them, sometimes they’re a response to a mentor, or to particular experiences.

But I do think such paternalism or maternalism is less prevalent than it was, in the US at least.

**You are a strong advocate of using information technology in healthcare, particularly regarding patient data. Can technology really be empowering for patients, and become personal healthcare assets rather than gadgets?**

There is a train of logic here, which starts with the availability of digitised healthcare information, which is now ubiquitous in the western world. The old truism that “information is power” applies, it’s a huge resource. The question is whether there are ways we can use this information to empower patients to make better decisions about their healthcare, both where they get it and how they manage their illnesses. I believe there is, but a lot of work needs to be done to make it possible. There are a lot of political, cultural and technical obstacles to sharing that data across boundaries and among institutions. This is true of the US, and for countries like New Zealand, the UK, and even in Denmark, which has worked hard to make it possible for patients to have their data.

The US has a peculiar problem: in our capitalistic healthcare system, competing entities, whether vendors or owning institutions, don’t like sharing data, which they see as a proprietary advantage. We are fighting uphill against market forces.

Privacy is another common concern. In the US there are no patient identifiers, unlike in Europe where there is enough trust in government to allow the creation of these unique patient identifiers for most patients. That makes sharing of information a lot easier, technically. This is the main obstacle we face.

One way forward politically in the US is to give patients their data and let them direct its use, because there is legislation here and a moral agreement that patients have the right to access their data and control it. Formal ownership of the data is not as important as access and control. Patients can have it, share it, do what they need to do with it. That is in some ways the ultimate patient-centred use of healthcare data.

Most people don’t want to manage the data, but they want to have it available when they need it. So we need an infrastructure to assist patients with managing their data . In the US that infrastructure could take the form of companies doing it for a fee, and there are ways of adding in technical supports, and decision supports to make the data more useful.

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**This all sounds promising, but with all that information in the public’s hands, is there not a risk of a divide building up between those who know what to do with the data and those who are less sure? Are ordinary people set up for this role?**

Yes, there are inequalities that are pervasive in our societies, affecting healthcare as well as other areas of life. In every country there are disparities, regardless of how free the care is, and they might affect this aspect of care as well. But to my mind it’s not a reason to forgo change. It really calls for other policies and provisions to reduce the effect of those disparities.

**You've watched a lot of technologies emerge in healthcare. Are there any that leap out as particularly influential or any in the pipeline you are excited about?**

In the history of modern medicine and technology, it is hard to get past information, as it is the lifeblood of medicine, it always has been. Information is a precious and rare resource that is fundamental to decision-making at every level. Many complex diagnostic technologies like CAT scanning or magnetic resonance imaging and all sorts of laboratory tests are all about generating information that is then processed in the brains of computers, which is to say, the brains of clinicians. So information is a fundamental, holistic technology .

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Even procedures we do are governed in real time by the information available to manage them. So we increasingly have simultaneous MRI imaging during surgeries so that surgeons can clearly see the full extent of a tumour and remove it.

Going forward, I think of information technology as the absolute core of progress in medicine. What we badly need, given so much digitised information, is analytic support for clinicians that enables them to make better decisions in real time, and for patients too. This verges on Artificial Intelligence but falls short of that, but I assure you that Google, Apple, IBM and others are all deep into creating AI to support the work of clinicians and patients.

**What about concerns over privacy and the abuse of people's data?**

I had to deal with this problem in government, and I came to the conclusion that privacy is a very strong human public concern, and that trust in whatever information systems we have is vital to their effectiveness. Creating that trust is a complex enterprise that involves educating the public about benefits and risks of collecting and using information, that the process requires action to protect privacy, but also transparency about the limits of our ability to secure absolute privacy. Whenever people share information online, financial, shopping preferences or whatever, they are taking a risk that the information will have some ill effect, that it could be pirated or just misinterpreted. The same will be true for healthcare, but there will be such amazing benefits from sharing it which outweigh these risks for the vast majority of people.

There are tens of millions of records that have been breached in the US in recent years, an astounding number. Most of the breaches are the result of what I call bad data hygiene. That could be poor practice by institutions in protecting that information, such as not observing basic security protocol, sharing passwords, being fooled by phishing, and so on. There is a lot to be done to improve this, but there will be hacks. There will be a constant technological battle between

criminals and mischief makers, and those who are protecting information, but we will just have to live with it.

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See notes for David Blumenthal's keynote address, Patient-Centered Care For High-Need, High-Cost Patients, at the OECD Policy Forum on Patient-Centred Health Care, 16 January 2017

\*Donald Berwick, president emeritus and senior fellow at the Institute for Healthcare Improvement (IHI), was also a guest at the OECD Policy Forum, 16 January 2017.