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Data Bolder tack needed to tap sources

Privacy fears limit e-health

Mark Eggleton

In a twist on the old highwayman demand of "Your money or your life" we finally have an answer when it comes to e-health. Our personal finances win while our health takes a back seat.

Right now most Australians when they want to get a snapshot of their financial situation can go online and find up-to-the-minute information on their bank balance and outstanding debts. We're pretty comfortable with the level of security afforded our financial details and even happy to give out further details if we're keen on purchasing goods or services. Unfortunately, we're a little leery about having our health records available online beyond what's stored in a computer on our GP's desk.

Security of data was one of the major focuses of the recent Big Data in Healthcare roundtable held by *The Australian Financial Review* in partnership with GE in Sydney with most participants agreeing it was an issue.

According to Australian Healthcare and Hospitals Association CEO, **Alison Verhoeven**, the best way to address people's privacy concerns is better communication.

"We have to be able to sell people a vision about why e-health is important to them," she says.

Furthermore, Verhoeven worries that while we continue to argue around the fringes of the debate we're falling behind as technology moves on.

"The focus of discussion around e-health is on the desktop versions of e-health. We haven't actually really begun to talk about the mobile versions of e-health so we're really constructing a system that works on old technology," Verhoeven says.

Part of the problem with Australia's roll-out of some form of e-health framework was the personally controlled electronic health record (PCEHR) set up by the last federal government was it

was poorly conceived and advertised, with very few Australians opting to participate.

Chief scientist at The George Institute for Global Health, Professor **Anushka Patel** says the best option would have been to give Australians the opportunity to opt out of the PCEHR rather than opt in.

In her experience in health services research it's often very difficult to get opt-in consent, logistically, and opt-out consent is frequently used.

"Very few people opt out. Even in situations where opt-out can occur later in the course of the investigations very few people opt out. That's a real test of whether people have real concerns such as privacy. I certainly think opt-out is the way to go," Professor Patel said.

Director of the Centre for Health Informatics Professor **Enrico Coiera** says people do have a right to be a little apprehensive about data security and part of the problem is health services, especially government departments, don't really "have their heads around the issue yet".

For Paul Nicolarakis, the principal adviser from Capital Markets CMC and former senior adviser to **Tanya Plibersek** (the previous government's health minister), the privacy question is an obvious concern. Yet he believes we have communicated the benefits of e-health in the wrong way.

"If e-health is valuable then it's the same conversation as immunisation. It's like everyone feels a bit of pain, you've got to get your injections, but there's value, which is you don't get sick."

"If we can start framing an e-health record, as immunisation has been so brilliantly framed over the years, then I think people will get it. The analogy runs right through to there even being a kind of herd immunity granted to the population when everyone or most people are on board. The upside for the community is massive, and I don't think that's been articulated that well," Nicolarakis says.



Interestingly, the US, which a few years ago was in last place in terms of implementing an e-health strategy, is now considered a leader in terms of policy sharpness and ensuring e-health has a positive impact.

"The US has built the idea of "meaningful use" into the core of their electronic health record technology.

"It's not talking about whether you have your boxes ticked in terms of what software you've got or what computers you have. It asks the question of whether the e-health record has a

amount of standardised data for clinical day-to-day care, resource utilisation, research and outcomes. It's now linked to the mobile health phenomenon and patients are using their own data via a mobile phone as a tool for improving their care."

Hannan says similar programs have been rolled out in a number of communities in developing countries.

"In Pakistan, we track the multi-drug treatment for tuberculosis right down to the individual house and patient.

We can monitor the food that's supplied to these impoverished people so they comply with their medication, all recorded on a mobile phone in a country with interrupted connectivity to the internet," Hannan says.

The roundtable panel agreed the great potential of e-health lies in the preventative health sphere where the use of non-health data such as our nutrition habits could help revolutionise our future health outcomes.

Professor Patel says we could potentially link the quite extensive databases that already exist.

"We already have one for everything that's available in any supermarket in Australia and a lot of that information was crowd-sourced - people with their mobiles.

"Link that to frequent user, loyalty programs that some of the big supermarkets have and we can look at what people spend at the check-out counter,

From left: Paul Nicolarakis, Enrico Coiera, Anushka Patel, the *Financial Review's* Paul Smith, David Dembo, Alison Verhoeven and Terry Hannan.

and you can very accurately predict how levels of obesity are going to change due to the composition of people's diet, their salt intake and more," she says.

"It allows you to target health outcomes at the policy level."

Unfortunately, this hardly gets mentioned in the more emotive debates around privacy and the supposed infallibility of clinicians.

"Most of the unexplained variation in health research is from people who believe their own clinical insights and experience is of greater value than what might be data driven or might be evidence-based," Patel says.

Verhoeven agrees and says moving our thinking away from anecdote-driven decision-making to data-driven decision-making is a real challenge for clinicians.

Professor Patel says the future starts now, but it requires a change of thinking across the profession.

"It is important this data driven approach to medicine is integral to the training of this current generation of doctors and healthcare professionals otherwise we're not going to get the cultural change down the track."

If e-health is valuable then it's the same conversation as immunisation.

Dr Paul Nicolarakis, health adviser

meaningful impact on patient care," Nicolarakis says.

Dr **Terry Hannan** from the University of Tasmania and Launceston Hospital has seen the meaningful impact more connected health and better use of data can have on a number of projects around the world. He was the co-founder of the largest e-health system in the world for managing the AIDS epidemic of 40 million people in Africa.

"We're now in over 200 countries in the world and we have a massive



Tim O'Meara.

"Whether staring down a microscope at the smallest possible level to health system research, the more data we collect, the better off we are. To use a sporting analogy, data allows us to not only see an individual sitting in the grandstand but all the people around them, the game and the interactions. We can get a complete picture and actually see what's happening," O'Meara says. Moreover, data can help drive more

collaborative research. A good example is the Alzheimer's Disease Neuroimaging Initiative (ADNI), which is driven out of the US but involves researchers from around the world.

"Rather than one research team moving to a point where another team can then begin their own research, it's all connected.

"Researchers can work in parallel rather than in sequence.

"Furthermore, they're sending multiple terabytes of data rather than just images to each other."

The potential to get a better understanding of the disease is huge. What's more, each team might be working with a cohort of patients, which not only gives researchers access to a global cohort in the tens of thousands but also a more diverse group of differing backgrounds.

In the field of health system research, O'Meara believes data's role is vast and virtually untapped.

"The challenge for healthcare is to keep people healthy regardless of their socio-economic status and we can now design a system that can break down socio-economic hurdles. We can move further into preventive health," he says.

Interestingly, the CSIRO is already utilising data and e-health in several trials in rural and regional areas. It's allowing Australians in remote areas to manage their own chronic diseases rather than present to primary carers or emergency departments as often.

O'Meara says that if a picture tells a thousand words, what data does is give you another thousand words of relevant and detailed information.

He says we should be closer than we are to rolling out a more connected, data-rich health system. "Just look at Medicare. It has collected a fair chunk of data and must be in the position to start using it."

MARK EGGLETON

Data points to top treatment

Tim O'Meara GE Healthcare's research manager Australia and New Zealand

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From the moment you present at your local GP, you're giving away data about yourself and your health situation, yet we rarely think twice

about it. We blithely hand over our Medicare card or nominate our health insurer without thinking twice about the amount of data we're giving away, yet there's general community apprehension about e-health records.

GE Healthcare's research manager Australia and New Zealand **Tim O'Meara**, wonders where the paranoia starts because if we were really worried about data security, we wouldn't probably present for treatment at all.

He says people do, generally, believe the data collected about their health will be used for their benefit but we have to communicate those benefits a little better.

"Quality of care will be so much better once we embrace big data in healthcare as we'll be able to deliver more efficient health outcomes to individuals and communities."

In research, O'Meara says data has a huge role to play at every level.