



Open up your internet connection and say 'Aaah'

By Chris Miles

Before the 2007 federal election, the RACGP called for an end to the delay in providing an electronic health record for all Australians. Midway through 2008, we have already seen a couple of big splashes in the e-health pond.

The internet search engine company Google officially announced its entry into the health care sector in May with the launch of Google Health. The company began developing a platform for consumers to store and manage their health records when it realised that one of the most common Google searches was for health information. (By this rationale, Google Sex cannot be too far away.)

Google's offering is similar to Microsoft's HealthVault; both services allow the patient to create a personal health record and share that information with doctors, hospitals and other health services.

Closer to home, one of the outcomes from the health stream of the Australia 2020 Summit in April was a concept dubbed 'Healthbook'. Inspired by the success of the social networking website Facebook, Healthbook is envisaged as an electronic health environment in which individuals can create their own health record and control who accesses it.

These are all examples of personal or individual electronic health record systems. They exist in various forms already. What Australia doesn't yet have is a national shared electronic health record which aggregates the data from a patient's multiple interactions with

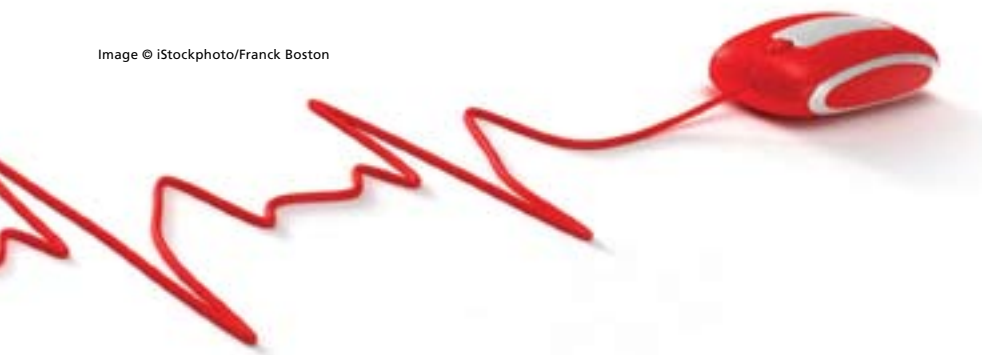
the health system and makes it available to GPs, other health care providers, and patients and their carers.

The 'rail gauge' problem

The road toward a shared electronic health record has been a long one, and one of the major obstructions has been the issue of messaging standards and interoperability – the capacity for different systems to exchange data using common and consistent formats.

Associate Professor Peter Schattner from the Monash University Department of General Practice suggests that a 'carrot and stick' implementation of standards such as those being developed by the

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National e-Health Transition Authority (NeHTA) would not only clear the way to making e-health systems interoperable, but would also help allay concerns about the privacy and security of patient information.

“At present we can’t send data held at doctors’ practices to other health care providers or patients and have it taken up by the receiving computer system because the different programs and systems don’t talk to each other. With universal standards they would, and then data could be held securely at a doctor’s computer, and forwarded on securely when an appropriate request is made.”

These interoperability barriers have been likened to the ‘rail gauge’ problem that hobbled colonial Australia, with railway tracks in one colony being wider or narrower than the tracks in the next, slowing the steam-powered wheels of commerce. Standardising the rail gauges was one of the arguments put forward for federating the colonies at the end of the nineteenth century. (In what amounted to a gloomy harbinger of state cooperation, Australia didn’t get its standard coast-to-coast rail gauge until the 1970s.)

Part of the way toward GP desktop software interoperability would be the introduction of agreed functional specifications for clinical desktop systems. What should clinical software record? What files or information should it transmit? The technical programming ‘hows’ would be the job of the software companies, but the ‘whats’ would ensure that systems talk to each other

and that clinical software components function the way GPs would want them to.

The RACGP is looking to develop these kinds of functional specifications for GP desktop systems – a set of criteria that would do for GP clinical software what the RACGP *Standards for general practices* do for primary health care, outlining the types of functions a desktop system should provide.

Dr John Bennett, a GP at the University of Queensland health service and member of the RACGP National Standing Committee – Quality Care, says that progress in Australia has been ‘patchy’, and attributes the failure of previous e-health ventures such as HealthConnect to a mix of political, cultural and technical issues. “There are the usual suspects that plague the rapid

uptake of e-health systems, especially in health care: the barriers between state and federal, primary and hospital, and public and private. If one looks at global progress overall in e-health, then Australia’s achievements are probably ‘middle of the road’. We lag behind Denmark and the United Kingdom, but are in advance of many other European countries and the United States.”

The computerised practice

The value of a shared electronic health record depends on GPs making use of computerised records systems. In this regard, Professor Schattner points to the importance of early work on computing in general practice conducted by Michael Crampton and Peter Maclsaac in association with the college. “Crampton and Maclsaac’s work focused on prescribing, which was very important. Once the government allowed scripts to be legally issued by computers rather than simply handwritten, the clinical software programs started to come into their own.”

By the mid-1990s, a college survey found that 45 percent of practices used computers for practice management tasks such as word processing and accounting, but fewer than 10 percent used computerised record systems.

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Professor Peter Schattner (right) says universal interoperability standards will help systems talk to each other and provide for secure data storage and transfer

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The landscape has changed dramatically in the last decade, and computers are a ubiquitous part of our lives; we can no longer be said to be in the dawn of the information age, but caught in its full LCD glare.

"It's hard to be precise about the figures," says Schattner, "but based on publications about a year ago, about 90 percent of GPs now use computers in their practice for any reason, perhaps 85 percent for any clinical purpose, and 40 to 60 percent for full electronic health records."

Our embrace of and reliance upon computers in our everyday lives also makes the web-based personal electronic health record – a record created or co-created by a patient and shared with health care providers – a more attractive and feasible prospect.

"In the simplest version of health information exchange, the patients themselves enter their information into a web record," says Enrico Coiera



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Networking goes healthy

Professor Enrico Coiera heads the Centre for Health Informatics at the University of New South Wales. His team is developing a prototype website that will achieve much of what Kevin Rudd's handpicked health leaders proposed at the 2020 summit in April.

"There are a number of levels of patient controlled health records," he says. "In the simplest version, the patients themselves enter health information about their allergies and so on into a web record. Then, wherever they go in the health system they can say 'here are my records'. The next level of complexity occurs when the patient and the GP both enter information into a shared record, and can both see what the other has entered. Veterans Affairs hospitals in the United States are doing this, for example, and have more than a million examples of personal health records up and running. The next level of complexity comes with health information exchange. The personal record now includes a set of links to records scattered across the health system. You as the consumer can control who sees which records and, for example, invite your GP or hospital to view your other health information. In this kind of model, it's up for grabs as to who actually holds the original information. It's likely to be a mixture of public and private as to where the data is held."

Coiera suggests that under the Healthbook model, some of the data may be held by GPs themselves.

"It depends on the final architecture, but GPs may be the custodians to some extent. There will be a certain percentage of the population who won't be interested in maintaining their own Healthbook or are unable to access these services, but we can easily imagine a trusted custodian setting it up and managing it for them, and the most likely custodian will be their primary care physician."

The Healthbook proposal builds on the rise in internet usage and developments in internet culture. People whose recreational internet use might previously have been confined to doing electronic banking, booking airline tickets online and keeping in touch with friends via email are now broadcasting their lives on sites like Facebook, MySpace and Twitter.

"There were early proposals for social computing more than a decade ago," says Coiera. "The ideas have been around a long time, but it's only now that we can say the public has had a real experience of social computing."

Coiera says that sites such as MySpace and Facebook have prepared the way in terms of making a web-based health information exchange something people feel comfortable with. These sites have also made the development task easier, giving programmers 'tried and tested interface designs' to work from. Coiera also suggests that the Facebook generation is less concerned about privacy issues.

Advertising and privacy

The launch of Google Health was dominated by discussions about data security and privacy. Google's position as one of the largest internet advertising portals has led to concerns about web-based personal health record systems becoming rich harvesting grounds for pharmaceutical companies, medical technology manufacturers and health insurers wanting to reach the right consumer at just the right time.

Coiera says there won't be any advertising on Healthbook. "It has no commercial funding, it's funded through the HCF Health and Medical Research Foundation." But Healthbook may be just one of many health information exchange sites to 'go live' in the next few years. Other models may emerge which have the potential to serve up targeted advertising.

While Google Health doesn't feature advertising as such, Coeira says the model for that service is designed to drive traffic to Google's search engine; the core of Google's business and, via the Google Ads provided along with search results, its main source of revenue. "The other concern is the potential to aggregate data for potential gain."

"The most important resource in a health care system after its health care workers is the information that has been collected about the patients using that system," says Dr Bennett. "The information must be kept in the hands of the health care system. I have considerable reservations about using a commercial service for such sensitive and important information, but if people choose to use such a service then it is their right to do so."

Progress on the personal electronic health record seems to be rushing past its beleaguered cousin, the shared electronic health record. Whatever doubts have been raised about the outcomes of the 2020 summit, Healthbook – or something like it – is happening. "Our goal is to have the first prototype ready by the end of this year," says Coiera. The prototype will use real clinical services data – enough to demonstrate how Healthbook works. A 'robust version' is planned to be online by the end of 2009.

Boon for biosurveillance

There are many reasons why GPs and other health care professionals are eager to see the shared electronic health record implemented, and why they're frustrated by the delays.

"Electronic health records allow individuals to share the most important aspects of their health information," says Dr Bennett. "This is particularly important for people living with a chronic disease, and their carers. It also gives us the ability to audit who has accessed someone's health information, a task that is very difficult with paper records. And it means patients are



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better able to participate in health care decisions, and can update or even 'correct' their record. An example might be a parent caring for a child with diabetes adding the child's latest blood glucose readings to the record."

A national shared electronic health record system will also provide valuable information in tackling public health issues. Bennett suggests that these systems will help toward biosurveillance for influenza or manmade biological weapons, and postmarketing surveillance of medications ('especially useful for rare but important adverse event detection').

For Coiera there is huge potential for public health outcomes even in the health information exchange model embodied by Healthbook. "The question is, what can you do once you have aggregated data to share and discuss? How can I as a GP use it to do public health analysis? One of the benefits of a Healthbook-type system is that it brings GPs and patients into the decision making loop."

These systems are still 'creatures in formation' according to Coiera. "But it's very clear that things are moving quickly, and we need to be aware

of it. We know that health information exchange is here; the question is, what's next?"

Meanwhile, there may be progress on the shared electronic health record front. Earlier this year, NeHTA signed a contract with Medicare to develop a 'unique health care identifier', a vital step forward in implementing a shared electronic health record and a way of joining the dots in the bigger public health picture.

"One of the important principles of 'information management' is that bits of data should be linked to each other in meaningful ways," says Professor Schattner. "To work out associations between variables, it is important to know who was the doctor and who was the patient. 'Pooled' data, where one doesn't know which GPs or which patients were included, doesn't allow for an equally meaningful analysis. For example, if I want to know if doctors who use the diabetes PIP incentives have better outcomes with diabetic patients who attend them predominantly for their ongoing care than GPs who do not use these incentives, it sure helps to know who is who." ♦

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