



Consumers  
Health Forum  
*of Australia*

# Health Voices

JOURNAL OF THE CONSUMERS HEALTH FORUM OF AUSTRALIA



eHealth:  
the future is now

representing  
consumers  
on national  
health issues

# Health Voices

*Health Voices* is published twice each year. Each issue has a theme that promotes debate on issues of interest to health consumers, government and industry.

Readers are encouraged to write letters to CHF in response to journal articles or other issues in Australian healthcare.

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## The Consumers Health Forum of Australia

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers.

CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF does this by:

1. advocating for appropriate and equitable healthcare
2. undertaking consumer-based research and developing a strong consumer knowledge base
3. identifying key issues in safety and quality of health services for consumers
4. raising the health literacy of consumers, health professionals and stakeholders
5. providing a strong national voice for health consumers and supporting consumer participation in health policy and program decision making

CHF values:

- our members' knowledge, experience and involvement
- development of an integrated healthcare system that values the consumer experience
- early intervention, prevention and early diagnosis
- collaborative integrated healthcare
- working in partnership

CHF member organisations reach Australian health consumers across a wide range of health interests and health system experiences. CHF policy is developed through consultation with members, ensuring that CHF maintains a broad, representative, health consumer perspective.

CHF is committed to being an active advocate in the ongoing development of Australian health policy and practice.

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# The evolution we need now



## Adam Stankevicius

It is at least 15 years since the federal and state governments began spending serious money on the development of a national eHealth system accessible by all Australians.

Since then, more than \$5 billion in taxpayers' money has been spent on this project. Yet the goal of attaining a system that would transform not only the national delivery of healthcare but also the patient's knowledge and influence in care decisions, remains some way off.

That no doubt partly reflects the inherent complexity of inserting an electronic records system into the heart of the unendingly complex world of healthcare, a record not only of life-sensitive individual health experiences but of the way the various providers involved — doctors, hospitals, diagnostic centres, aged care facilities and the rest — interact with the consumer and with each other.

The significance of this challenge is also explained by the dawning recognition of the potency of information technology to change fundamentally the relationship between clinician and consumer. Placing medical records within the control of individual consumers opens the way to transformational change which will underpin shared decision making and which the evidence indicates will be good for patient care and for doctors.

Above all this, federal-state/territory indecision and lack of strong governance and accountability throughout the system would always mean that such a complex project would struggle. Even so, the success of Northern Territory's eHealth system, begun nine years ago, has shown the way.

CHF has argued long and consistently for a personally controlled eHealth record because of the big advances it

brings to patient care and consumer influence. CHF believes individual citizens should have to opt out of, rather than opt in to, the scheme as the current arrangements requires. Further, CHF's arguments for the patient to retain control over what goes into the record and who can view it, as well as swift access to diagnostic results, have largely won acceptance in the face of resistance from elements within the medical profession.

In this edition of *Health Voices*, we have sought to reflect a broad range of significant experience and informed opinion. While the concerns about the impact of eHealth remain significant, whether it be over disappointing progress so far, privacy issues, or the lack of attention to allied health services, there is unanimity about the substantial benefits eHealth offers.

The report of the Government's review panel into the personally controlled electronic health record released earlier this year has presented a potential circuit breaker in overcoming barriers to roll-out of what the review now terms the My Health Record, or MyHR.

CHF welcomed the report because it provides a plan that appears more likely to cut through some of the inherent obstacles in the current process, such as the unwieldy governance arrangements and the opt-in provisions.

In this issue of *Health Voices*, Dr Steve Hambleton, a member of the review panel and now chair of NEHTA, gives an upbeat view, that "we are on the verge of something that will be fantastic for our health system and will deliver some of the long term structural savings that we really need".

That view, coming from an individual with Dr Hambleton's record, deserves respect. And he sets out some compelling evidence why Australia needs to crank up eHealth: average patient interactions with the health

system each year total an eye-opening 22. These include four visits to a GP and 12 prescriptions.

However the lack of a cohesive approach to healthcare records significantly increases risk of errors: almost two million Australians experience an adverse drug event each year, and about 200,000 of those end up in hospital.

These are persuasive reasons for the introduction of information technology that is standard feature of most spheres of modern life.

As the review stated, personal eHealth records would:

- Improve patient safety
- Remove wasted time in accessing information
- Reduce duplication of and unnecessary treatment
- Reduce pressure on healthcare workforce
- Better coordinate care

The consulting firm, Booz and Company last year estimated that more than \$7 billion in direct costs could be saved annually by digitising the health sector. That would also bring substantial improvements in patient experience with millions of hospital visits and admissions avoided each year.

These are profound indicators of the potential of eHealth, and make all the more unacceptable the lack of progress.

CHF has welcomed the change in focus of the medical record and its name to reflect more of a partnership between clinician and consumer.

The reluctance of the medical profession to participate in an arrangement which gives the patient power to include or omit information has prompted the review panel's suggestion of a "flag" in the record to indicate when a document has been hidden and is only visible to the original practitioner who uploaded

that document. Importantly, CHF has consistently recognised that eHealth record is no substitute for effective communication between consumer and clinician.

GPs have also pressed for an Authority to Post regime to retain their control over the display of diagnostic results on the patient's eHealth record.

CHF argues that Australia is already out of step with other western nations where such results are provided to consumers as a matter of course. The explanation of tests and potentially

bad results should be a part of the informed consent process before the test. Withholding them from patients until a doctor can 'curate' them is unacceptable.

Again, CHF believes there are compromises which can be reached to ensure patients have maximum, reasonable control over their records.

The doctor's concerns hark back to longstanding traditions of medical oversight and authority which have provided the background to the inertia that has delayed the delivery of a 21st

century health system that would save lives and dollars.

It is time for all of us to move forward. Or move on.

*Adam Stankevicius is CEO of the Consumers Health Forum of Australia.*



## Doctors: It's time to connect

### **Mukesh Haikerwal**

I have worked in general practice for over 20 years in the west of Melbourne.

I came to the realisation that the work that I do, the accuracy of it, the necessity to manage the volume of information and to properly monitor the care of my patients can be greatly enhanced by using technology. Over the years general practice has evolved to a place where 98 per cent of GPs would use technology for clinical purposes.

This started with patient demographics, age/sex registers to monitor several disease groups, some practice management and the most transformative change in using computers: to prescribe medications. Not only were these more legible, accurate and clear, they enabled access to databases of medications, doses, drug information, drug interactions and eased the complexity of prescribing medications such as the pharmaceutical benefits authority scheme.

The use of technology in general practice therefore has progressed to a level where almost all of our pathology and radiology and some of our communications from specialists, allied health providers and, very rarely, hospitals come to us in electronic

format. This brings with it the benefits of accuracy and timeliness and hopefully a real-time review of the multiple episodes of care a single patient will have from multiple healthcare providers.

In my time with the Australian Medical Association I was a proponent for supporting the uptake of technology in the healthcare space otherwise known as eHealth. As national president we worked with an expert advisory group to help this agenda. I was also appointed to the Health Minister Tony Abbott's Ministerial advisory group on eHealth.

Later I was appointed to work with the National eHealth Transition Authority where I worked from 2007 to 2013. In NEHTA I expended great effort in engagement with the community – consumers, clinicians, policymakers and the IT industry – building a 'dream' for eHealth, a 'thirst' for this and great expectations for better health outcomes for individuals and the healthcare system.

There was a widespread optimism through the consultations for the National Health and Hospitals Reform Commission that gave the whole sector confidence that what was being proposed would benefit the working

lives of those in the health system and the consumers they cared for.

The PCEHR system went live on 1 July 2012. The initial impact was minimal and the commentary surrounding this was "this was a marathon not a sprint!"

PCEHR enrolments now total almost two million people. What is not clear is how many of those who have enrolled actually know that have a record, have had a look at it, understood the levels of security that they have within it and have availed themselves of those settings. Although many millions of documents are quoted as being "available through the PCEHR", the vast majority are actually administrative data accumulated by Medicare from medical and pharmaceutical benefits paid. The number of clinicians actively participating in the system is still paltry as is the number of actual clinical documents (under 40,000) generated by clinicians.

There are multiple user issues for consumers and clinicians alike.

Subsequent to the Federal election the Richard Royle Review was commissioned and reported to the Federal Minister. This report was widely canvassed within the clinical and health ICT communities and apart from faint



murmurings it is pretty well accepted as the way forward. The Department of Health then embarked on a consequent review of the review, the outcomes of which are not yet clear.

More than two years have passed since the “go live” for the PCEHR system. It is also over a year since the Federal election. The need and thirst for the proper use of technology in healthcare system still exists. The benefits will still accrue and are badly needed in the context of significant strains on the public purse, increasing health expenditure across the system with limited government funding, increasing levels of chronic and complex diseases stemming from epidemic rates of non-communicable diseases, an ageing population, and the demands of advances in medical science.

Not a day goes by in my practice where access to timely, up-to-date, cogent, trusted information would not contribute to multiple patients’ care within and outside our premises. We still marvel at the longevity and centrality of the fax machine since its inception in the late 1980s only in our sector! We squirm at the paper warfare in our dealings with the healthcare system as clinicians and indeed as patients trying to navigate the unnecessarily complex so-called ‘system’. In worldwide comparisons Australia’s healthcare

system performs extraordinarily well — more because the people within it and despite the systems: not because of them!

The Royle review report has many commendable directions which bring greater accountability to the system, a more consumer-facing approach to working with the PCEHR. It acknowledges that PCEHR is only one component of the health system that uses technology, not the complete shooting match. Nor is it in any way the “killer app” - unfortunate term though this is.

We who use the healthcare system as consumers actually use technology and devices in every other aspect of our lives. We will absolutely like to have the ability to look at information about our healthcare, take control of the healthcare that we have provided to us and the healthcare professionals that we recruit to care for us with the aim of making better healthcare choices.

As a clinician working in general practice, I would dearly love for all other participants in healthcare to also participate using technology when they communicate with me so that I can communicate in that way with them. This can be done tomorrow using existing secure encrypted email system from one clinician to another. Other

enhancements include the use of mobile technology and telehealth incorporating video.

These are not advances to fear but to embrace. They have to be built to the needs of the healthcare providers who will make decisions based on them, who will be personally liable for deficiencies that may become apparent and who will wear the consequences. This can only happen with the clinical community determining what technology they need, and how it should be used and which parameters need to be applied. Clinicians know that there is a role for the health technology sector, of course, to build and partner in this process. Clinicians must be the group allowed to determine clinical practice.

*Dr Mukesh C Haikerwal, AO, is a practising GP and chairs the Council of the World Medical Association. He also chairs the Australian Institute of Health and Welfare and is Professor, School of Medicine, Faculty of Health Science, Flinders University, Adelaide. He was the 19th president of the Australian Medical Association and is a member of the board of Brain Injury Australia.*





# Breaking through the information barrier in healthcare

## Delia Scales

As a retired nurse with a background in neurosurgery and intensive care, it was not until I got breast cancer that my eyes were truly opened to the cost and information barriers confronting health consumers.

In 2007, a GP found cancer in one breast and instantly referred me to an expensive private breast cancer clinic. There was no discussion of cost or quality. I quickly went through \$10,000 in unexpected out-of-pocket costs, despite having paid private health insurance for thirty years. The specialists were uninterested in my bills. The nurses had no idea about the side effects of cancer treatments. My complaints about lack of education, health assessments and symptom management were brushed off. I ended up in the public health system, broke, chronically unwell and confused.

This information black hole amazed me. In a world where all sorts of detailed information, from bank balances to hotel bookings, are instantly available electronically, the absence of accessible information on the life and death issues of healthcare is unacceptable. It stirred my interest in looking into the potential of IT to bring this information to our screens.

My site, [wikihospitals.com.au](http://wikihospitals.com.au) is aimed at deploying the power of eHealth to give consumers the best health deal. That is the first step. I am campaigning to develop an app that is based on community feedback concerning cost and quality and using integrated software to generate a five star rating system.

With eHealth slowly taking root in Australia, patient influence is on the rise. The Government's Personally Controlled Electronic Health Record has the potential to give patients more

information and hopefully better insight into their medical care.

I discovered that my private cancer treatment had varied dramatically from the standards of care I would have been given if I had gone public for the same condition. Why should not such vital and expensive matters be available for everyone to access easily when they need to?

Unnecessary and expensive tests had been ordered before any surgery; full body CT's with contrast, nuclear-med bone scans, liver ultra sounds and chest x-rays. Lymph nodes were surgically removed without any testing to check if they contained any cancer. Chemotherapy for well-contained grade one cancer ordered, despite it providing me with a '2% risk reduction'. No pre-chemo education or any health assessments were ever given despite paying thousands for this private treatment. I was never reweighed during chemotherapy and despite losing 15% of my body weight, my dose was never changed. At every point of care, my treatment fell well below best practice guidelines. I concluded that I had been used as a money making scam, at the most-vulnerable time in my life. Angry and shocked, I began to investigate.

Senior oncology nurses told me that private patients often turned up in public hospitals, broke and distressed. 'People make the mistake of thinking the more they pay for healthcare the better is it, and this simply isn't true'. Private hospitals were described as 'completely financially dependent on the money that private doctors bring in' and therefore incapable of setting clear clinical standards and forcing doctors to follow them. Private doctors were described as operating in 'an insular and out of date culture' with very little supervision or peer reviews of their work.

Health department bureaucrats told me that attempts to investigate private hospitals were blocked by 'intense lobbying from medical, business and political groups'. Cancer lobbyists told me that private hospitals refused to collaborate with research projects into the care of patients. Cancer community groups knew about lack of qualified nursing staff and a health team approach in private hospitals. Nobody would speak out publicly.

There was no way that I could have known that this problem exists. The majority of cancer treatment is now private. The secrecy surrounding bad hospital treatment just perpetuates the problems. Every day more people are damaged, by the same bad hospitals, delivering the same bad care. It doesn't have to be this way.

I concluded that the only solution was to start a website explaining 'what should happen' when people have hospital treatments, in terms of easy to understand Best Practice Guidelines. This information is currently hidden in hospital manuals and obscure professional guidelines. The website could point to common errors that occur to patients, so people know what to look out for. It could discuss the likely features of a 'good' hospital and how to identify and avoid 'bad' hospitals.

My intention with WikiHospitals is to promote whatever it takes to bring simple, accessible information on our health services choices to consumers in a way that helps them make the right decision for them.

There has been an explosion in web sites and apps offering to help health consumers through the thicket of decisions and choices to be made with medical care. (*See list in accompanying box, Online Sites For Health Consumers.*)

My advice to health consumers is to come together and support a public consumer rating website for hospitals, where cost and quality can be openly discussed. This is the only way to break down the secrecy, expose bad practice and make healthcare safer and more accountable.

*Delia Scales has a Bachelor of Nursing Science, University Melbourne, a Grad Cert Neuroscience, Australian Catholic University and in Transition to Intensive Care, Monash. After private cancer treatment, she left nursing and at her own expense started the blog Wikihospitals and the YouTube channel to provide consumers with healthcare and cost information not available elsewhere. She currently is campaigning through the Pozible website, to raise funds for an app, giving patients clear information about cost and quality of healthcare.*

## Online sites for health consumers

Medical records and self help apps  
Best of British startups  
Managing multiple sclerosis  
Pricing of medical services  
Apps and personal alarms for aged care  
Medical practice software  
Managing diabetes with apps  
Technology to help with cancer treatment  
Apps and cardiac arrhythmias  
Hospital software for smart wards  
Medication safety and apps  
Teleconferencing — faster and cheaper  
What is health IT?  
Safe patients and hospital software  
Get Better  
GenieMD  
One state in America  
Links are available in the online version of *Health Voices* on [www.chf.org.au](http://www.chf.org.au)

# If you suffer from a chronic illness, an eHealth record is important to you



## Steve Hambleton

The difference eHealth can make to patient care is amply illustrated by the potential benefits to those with complex and chronic disease who need to see multiple providers.

Clinicians are now experiencing first-hand how a PCEHR can make a difference to patient care, particularly in complex cases.

Take the case of Kevin. Brisbane based GP Dr John Aloizos<sup>1</sup> registered one of his patients, Kevin<sup>2</sup>, for an eHealth record in his practice. Kevin is a 48-year-old diabetic with comorbidities including renal failure and hypertension requiring extensive ongoing treatment.

A couple of weeks later Kevin experienced a cardiac event whilst at Redlands Bay Hospital attending one of

his thrice-weekly dialysis appointments and was transferred to the Princess Alexandra Hospital.

Following treatment Kevin was discharged and his discharge summary uploaded to his record. The PCEHR flag on Dr Aloizos's Clinical Information System showed up as green, indicating that the record had been activated.

Dr Aloizos visited Kevin at home and by viewing and downloading the Discharge Summary saw immediately that five of Kevin's medicines had been altered during his hospitalisation.

"I was able to prepare and print the prescriptions for the new medicines and use the Discharge Summary as a checklist when I visited Kevin and reviewed the medication changes. Without this information I would not

have been able to provide the follow up care I needed to," said Dr Aloizos.

Uploading a new Shared Health Summary into the eHealth record system ensured the medication list was accurate and up to date in the event other healthcare providers involved in Kevin's care accessed the system.

Using information from the PCEHR, Dr Aloizos was able to improve the quality of care he provided to Kevin and eliminate the cost of having to visit Kevin a second time if that was required after he received the discharge summary.

A huge amount of investment has gone into IT in this country, and I think there is a real necessity to make sure we exploit the investment we've made so far and get outcomes that are meaningful.

NEHTA has delivered the solid foundational products that are the basis of a robust eHealth solution. These are the individual healthcare identifiers, the medicines and diseases terminologies, secure messaging, and the background infrastructure. This has, in effect, created the national eHealth rail gauge (and some of the rolling stock) for securely transporting and sharing clinical information.

I strongly believe we are on the verge of something that will be fantastic for our health system and will deliver some of the long term structural savings that we really need. Widespread adoption and utilisation of national eHealth standards and protocols will allow us to communicate better and more accurately and gain efficiencies across the sector.

I was fortunate enough to be part of the Government's review panel into the implementation and uptake of Australia's personally controlled electronic health record (PCEHR) system. The review was chaired by Richard Royle. The review released in May 2014 contained 38 recommendations to address shortcomings of the system and make it more effective for doctors and patients.

Overall, we found strong support for a consistent and effective shared electronic health record for all Australians. The feedback I am getting from Government is also positive and shares my view that eHealth has a strong future.

Importantly, the right people need to be registered—those with complex and chronic disease and those who need to see multiple providers. Having a system where we can access a patient's medical information quickly would make our job quicker, safer for the patient and more efficient.

Changing demographics and the increasing prevalence of chronic and complex disease are driving demand for more services. In order to continue to have a sustainable system we need greater efficiency and effectiveness in healthcare delivery which is exactly what eHealth promises.

Every year Australians have an average of 22 interactions with the health system, including: 4 visits to a GP, 12 prescriptions, and 3 visits to a specialist. Most of the information from these interactions with patients is held in separate clinical information systems, with a mix of hard copy, paper-based records. Most of these records can't be shared electronically from practitioner to practitioner.

Research into medication safety indicates that significant patient harm and sub-optimal use of medicines frequently result from the discontinuity that occurs when patients visit different healthcare providers.

The lack of a cohesive approach to records management significantly increases the risk of errors such as misdiagnoses, lack of awareness of adverse reactions to treatment, and the over-prescribing of medications.

Almost two million Australians experience an adverse drug event each year and approximately 200,000 of these end up in hospital. Clinical studies have proven that adverse drug events can drop by up to 60 per cent through better surveillance of prescribing behaviour. This is why access to a patient's medication history is so important!

NEHTA's work for the next 12 months will focus on adoption and meaningful use—creating a critical mass of users who are connected and meaningfully using eHealth to deliver better healthcare. While quality and safety

benefits remain essential, there needs to be strong emphasis on ensuring that reliable information from a connected community of healthcare providers is available in the record.

I see a lot of opportunity for eHealth to deliver better clinical outcomes for patients. As former AMA President and a member of the PCEHR review panel I see it as a natural progression to accept the role of NEHTA Chair and to provide the NEHTA Board with a direct connection to my colleagues at the front-line of Australian healthcare.

*Dr Steve Hambleton MBBS FAMA was appointed Chair of the National E-Health Transition Authority (NEHTA) in June 2014. He is the former Federal President of the Australian Medical Association (AMA) 2011–2014. Dr Hambleton is a Brisbane GP. He was a partner in the Continuous Care Medical Centres group and State Manager of the corporate medical centre provider Foundation Healthcare in Queensland (now IPN). He was President of AMA Queensland in 2005–6. Dr Hambleton has served on various national bodies including as member of the National Immunisation Committee and the Pharmaceutical Benefits Advisory Committee. He chaired the AMA Taskforce on Indigenous Health from 2009 to 2014. He is currently a Member of the Clinical Care Standards Advisory Committee of the Australian Commission on Safety and Quality in Healthcare and a member of the Australian Atlas of Healthcare Variation Advisory Group.*

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1 Dr Aloizos is also a Senior Clinical Governance Advisor with the National E-Health Transition Authority (NEHTA)

2 Not the patients real name



# Wanted: strong Government support



## Catherine King

It's now been five months since an expert review of Personally Controlled Electronic Health Record (PCEHR) found that e-health records were a piece of critical national infrastructure.

This was clearly not the outcome Minister Dutton was looking for, which might explain why it took him six months to make its findings public, and who knows how long to respond and provide any guidance as to what his government might do to advance eHealth.

In opposition he denounced eHealth as a "scandal" but signs the review was not delivering the result he wanted became clear in March when the minister gave a speech declaring "the government supports the principles of eHealth and the potential for it to drive greater productivity and sharing information across the healthcare system, particularly through electronic prescribing and paperless claiming."

Precisely. But he then followed this by allocating a paltry \$140.6 million to keep the eHealth system going while the government acts on the recommendations of the review.

It was a clear sign the government wanted merely to keep eHealth on life support while he works out how to match his pre-election rhetoric, with the shocking finding electronic health records are actually a pretty good idea.

Which is a great shame, because with government encouragement and support, eHealth still holds out the prospects of revolutionising healthcare delivery in Australia, while making the system sustainable and better for patients.

Denmark has taken around 20 years to get this right, but the benefits have been enormous. Every patient and doctor is now signed up. Clipboards

and filing cabinets have been replaced with handheld wireless computers. Any doctor can now instantly access the full medical records of any patient, including their allergies and adverse reactions.

As far as eHealth is concerned the lesson is that persistence pays off, a lesson clearly lost on the Coalition.

Australia too has been talking about eHealth for 20 years. The problem is, for much of that time we've had Coalition governments which haven't taken it seriously.

Way back in 2003 when Tony Abbott was Health Minister he declared "*Failure to establish an electronic patient record within five years, I said, would be an indictment against everyone in the system, including the Government. I hope to be judged against that somewhat rashly declared standard; not because it is likely to be fully met but because it would mean that, come next year, I remain the Health Minister!*"

In that one paragraph Mr Abbott revealed both his contempt for the health portfolio and his failure on eHealth records.

No surprises then that it actually took a Labor Government to establish the architecture and actually deliver an eHealth system.

That is not to say Labor got everything right. The review identified a number of issues that need to be tackled, chief among them how to encourage doctors and specialists to upload all their records, and persuade a lot more patients to sign up.

But the review's findings were unambiguous – eHealth could save the health system \$7 billion a year through fewer diagnosis, treatment and prescription errors, and in the process avoid thousands of unnecessary hospital admissions.

Saving lives AND improving the Budget bottom line. What government wouldn't back this?

Well, a Coalition government, it seems. It's a view not shared among health industry professionals and consumer advocates who overwhelmingly support the continuing implementation of an electronic health record for all Australians.

Notwithstanding the doomsayers there are, at last count, at least 1.66 million people with an eHealth record and 3,000 to 4,000 people joining every day.

Imagine how much better this take up rate would be with a government that actually promoted eHealth records. But sadly, as was confirmed at Senate estimates earlier this year, the government has no "immediate plans" for publicity or education campaigns to boost voluntary take-up numbers.

In March, when Minister Dutton was still sitting on the report, then AMA president and member of the review panel Steve Hambleton warned "eHealth is really on hold at the moment in Australia...everything is waiting on clarification as to the direction."

The expert review shows the PCEHR has been successful but what it now needs is a government prepared to abandon its politically driven attacks on eHealth and wholeheartedly get behind the scheme.

*Catherine King is the Shadow Health Minister. She has been a Parliamentary Secretary for Health and was Minister for Regional Australia, Local Government and Territories in the second Rudd Government.*

Health Minister Peter Dutton and Greens health spokesman Richard Di Natale were also invited to contribute to this issue of Health Voices.



# Why I love eHealth

## Melissa Cadzow

I have loved technology my whole life. My parents set up one of the early technology companies in the 1970's, so like today's kids, I've always had technology around me. My own technology business is 24 years old. So, naturally enough, as a consumer representative I have a particular interest in eHealth.

"eHealth" means many things to many people. I've adopted the broad definition regarding how technology can help healthcare.

Let me explain why I am excited about eHealth. My story starts in 2009 when I suddenly became my Dad's carer for his last two years. During that time he had two bouts of cancer, heart issues, blood poisoning, lung and hip surgeries. He used to joke he was collecting specialists; we had six at the same time at one stage. He also collected hospitals: two public, two private and finally a hospice.

Having correct information about his health on hand was important. We were often showing the various health professionals copies of letters or tests that the specialists and health services had said they would send one another.

I was soon carrying around a fat folder of valuable information. It soon expanded to two folders. But my fear was that we could easily lose them, or that Dad would be admitted to emergency yet again and the folders would be somewhere else.

So, being technology minded, we developed our own customised eHealth record, summarising the visits but also including copies of all letters, tests and anything else that was useful. We could access it via computer, iPad and iPhone. Remember this was three to four years

ago, back when smartphones were only just becoming popular. His health information was literally in my pocket.

Technology made a big difference to his healthcare, but so did two pages of paper. We found it important to maintain an up to date two-page printed summary, listing conditions, current medications, specialists etc. I printed many copies of this two page summary – for his and my wallets, for the car, in our homes. These were dated and kept up to date.

Having correct and up to date information on hand made a major positive difference to his care. I've continued with this system for the rest of my immediate family. My husband and I can access each other's information, and of course, the kids'.

In the two years since Dad died I've been trying to get the consumer voice heard in eHealth discussions.

I would like to briefly discuss the major eHealth systems at the [National](#) and [South Australian](#) level.

I signed up with the national Personally Controlled Electronic Health Record (PCEHR) in the first few days of its launch back in 2012. I also linked it to my children's records. Luckily we only have run-of-the-mill illnesses. I've logged technical issues via their hotline over the past two years, and another consumer representative has kindly helped me bring them to the attention of more senior staff, after which the department has contacted me a number of times to explore the issues in detail, including having experienced problems in the My Child's eHealth Record iPhone app.

As consumers, it's our health data, we need access to it, to be able to control it, to be able to rely on it, and to have useful information in it.

So with the national eHealth record I am taking a wait-and-see approach. I log in and review the data, watching detail flow in (prescriptions, Medicare consults, and immunisations). If they can pull it off successfully it will make a massive difference to both health professionals and consumers. But in the meantime I will still track my family's health details my own way.

Now to my home state: South Australia. I am excited about how SA Health is implementing a new eHealth system within SA's public system. It is called EPAS (Enterprise Patient Administration System). As a consumer representative I have seen a brief demonstration. I feel that once it has been fully implemented, tested and customised, and then once the health professionals are used to it, it should make a marvellous difference to healthcare, particularly for the "frequent flyers" in the public system. As with other hospital systems around the country, discharge summaries will be sent to the national eHealth record. It is early days yet; it has only been introduced to a couple of public hospitals in South Australia.

In general, both at state and national level, done correctly, eHealth systems will make a positive difference to healthcare. But as with most technology projects, if it's done too quickly, without enough testing, or has bad design, not involving consumers in a meaningful way or not getting the health professionals on board, trained and supported, then there is potential for harm.

As with other areas of health, it's important that consumers are involved in eHealth projects. As shown by the evidence list collected by Cancer Australia (<http://consumerinvolvement.canceraustralia.gov.au/health-professionals>), consumer feedback and

suggestions are often surprising and can lead to major improvements in quality and safety.

If you are a consumer representative serving at a state or national level please consider raising the topic of eHealth in your board or committee meetings; whether it's your health service's internal system, PCEHR at a national level or some other part of eHealth.

I am excited about the future of eHealth and thank CHF and the senior consumer representatives for their work in this area.

*Melissa Cadzow serves on South Australian and national boards in the areas of business, information technology and health. She has over 25 years of business experience with her IT company and currently serves on the Australian Broadcasting Corporation Advisory Council, Australian Community Pharmacy Authority, Women's and Children's Health Network Governing Council, Australian Health Practitioner Regulation Agency Community*



## Overcoming the tyranny of distance



Marg Brown



Lesley Reilly

### **The views of two consumers living in rural Australia.**

*Marg Brown of South Australia writes:*

In considering what to write in this article, I was reminded of a serious episode in my own medical care.

It occurred as I was being prepared for a cardiac procedure.

After filling out copious forms at a private hospital admissions department, I eventually found myself on the table facing a specialist cardiologist for day surgery.

The procedure of investigation and insertion of a stent in my heart was explained. Things were underway, when

all of a sudden the specialist grabbed my MedicAlert bracelet.

Everything stopped. It was then explained that I was not able to have any dyes put through my kidneys, and I would have to come back another day, to give the specialist time to consult with colleagues. The MedicAlert bracelet saved me!

If I had not been wearing that bracelet the outcome would not have been so positive, perhaps resulting in my having to go on to dialysis.

BUT if I had had a Personally Controlled Electronic Health Record (PCEHR), which would "follow me" from rural, remote and urban settings, the issue

would have been brought to the cardiologist's attention.

Throughout rural and remote Australia patients are frequently retrieved/airlifted, and or taken by road ambulance and I can see so many positive outcomes for both patients and health professionals who are responsible for their care. People need a PCEHR, or maybe the suggested new name My Health Record (MyHr), which they own and control.

When a patient returns home, or to their local hospital, they require a discharge plan. Sometimes these plans are not available straight away and the GP requires the information there and then.



Through the PCEHR, however, discharge planning and medication information will be there!

Once patients are in a health unit, especially if they are critically ill, they do not really have a lot of control over the information required to assist those who are dealing with their care, and therefore PCEHR is a very positive tool.

At present consumers need to be talking with their general practitioners about how, they and their GP, can become involved, that is if they have not already done so.

I have been a member of PCEHR Independent Advisory Council, and even before that I have had a particular interest as a rural and remote representative on various health committees, because I believe in the necessity to improve rural and remote consumer/patient transfer and admission to major teaching hospitals. An electronic record, to which you, the patient, have access, can only help.

If you have not considered searching for the information and perhaps even registering for a PCEHR, why not "have a look"?

*Margaret Brown AM lives on a property in the SA Mallee. Lameroo, the nearest town, has a hospital, but does not have procedural or obstetric services. As a community representative, not in an employed position, she supports consumer participation and representing rural and remote consumers, advocacy work for which she was honoured with an AM. Her memberships include: National Advisory Committee for the Centre of Research Excellence in Rural & Remote Primary Healthcare, PCEHR Independent Advisory Council, Chair Health Consumers of Rural & Remote Australia, Deputy Chair Health Consumers Alliance SA, Community & Student Liaison Flinders University Rural Clinical School PRCCs, Director NT General Practice Education & Training Ltd. Board, Breast Screen SA, SA Dental and AHMAC National Oral Health Plan Monitoring Group.*

*Lesley Reilly of the Northern Territory writes:*

An eHealth system has been in use in the NT for some years now so we are experiencing the benefits but also the challenges of this development.

The recommendation to adopt an opt-out system for PCEHR would

remove some of the difficulties being encountered with the current system. No registration would be required, alleviating the need to allocate a huge amount of time and resources to register clients. Even very IT-savvy people found the online registration process a challenge. It is complex and not well thought out: difficult for people with English as a second language, those who lack access to a computer, and those who may be illiterate.

From a consumer perspective, there seems to be a general acceptance and appreciation of the value of having a personal electronic health record, without much anxiety about the privacy issue. In fact, secure electronic messaging will be a big improvement on faxes that can be lost or just left lying around.

To have a record of current medications, allergies, adverse events, immunisations, medical history and discharge summaries that are accessible by both the individual and their healthcare providers in any location in the country could be potentially life-saving. Pathology and diagnostic imaging results, that are alerts in medical history, should be built into the system without delay.

Especially important to Territorian patients would be to have discharge summaries from interstate hospitals recorded, as well as discharge summaries from local hospitals to GP's and remote clinics. Historically, patients have often been disadvantaged when such summaries are not received in a timely manner. I have encountered patients from remote areas who have developed post-operative complications after returning from interstate, and have presented to the ED at Alice Springs Hospital only to find there is no record of their recent hospitalisation and treatment.

Clinicians need to upload data in a timely manner, to see it as a necessary part of their duties.

The NT Medicare Local eHealth team have been introducing the national e-Health record system to consumers and private healthcare providers across the Northern Territory. They have focused on resourcing and supporting general practices, specialists, allied health professionals, aged care facilities and community pharmacies to connect with the national eHealth record system and to inform and register urban consumers.



Issues that have been identified include how to register children who aren't on their parents' Medicare card. There are several thousand children who couldn't be registered. Now guardians can sign up a child individually.

Remote communities affected by the Federal Government Intervention have found themselves required to do so much reporting that this has resulted in much wariness, for example with notifiable incidents. What access would there be to the record, and what could that access initiate?

As the PCEHR implementation continues, more input and consultation should be sought from the general public, not necessarily the very technically literate, to determine what works and what doesn't work with the system.

*Lesley Reilly lives near Alice Springs. She arrived in the Northern Territory in 1973 and lived and worked on remote aboriginal communities for 14 years, leaving her with a deep interest in remote health issues. Breast cancer brought a deeper understanding of the impact of spending many weeks away from home having treatment, particularly for Aboriginal people who have English as a second or third language, and find themselves isolated from their community. She is involved with Bosom Buddies, is a member of the Palliative Care Association, and consumer advisory groups associated with General Practice Network Central Australia now of NT Medicare Local.*

# Potential for benefits and risks to safety and quality



## **Prashan Malalasekera**

The expansion of electronic health has been one of the defining narratives in healthcare provision over the past decade. “E-health” provides significant opportunities for enhanced consumer involvement in their healthcare. It is also cited as a crucial tool to tackle some of the most pressing challenges facing global health systems today: rising costs, chronic and complex disease management, and the information bottlenecks between healthcare providers in today’s health system.

The Australian Commission on Safety and Quality in Healthcare (the Commission) is particularly conscious of the potential benefits to patient safety that the appropriate and considered use of e-health can bring. There is evidence to suggest that e-health tools, such as electronic health records (EHRs) and electronic medications management (EMM) can increase patient safety and improve the quality of care provided to consumers. For example:

- some research has focused on the ability of e-health to lead to reductions in medication-related adverse events through improved legibility of prescription information
- consumer-centred electronic medical records with care plans, timely treatment and diagnostic information can bring us closer to providing the right care at the right time
- prompts for tests and medications for consumers presenting to an Emergency Department with a heart attack, alerts for allergies in prescribing systems, and appointment reminders can improve care and outcomes.

In Australia, the conversation around the benefits of e-health is closely tied to the discussion about greater consumer participation in their own care. The Personally Controlled Electronic Health

Record (PCEHR) is designed to give health consumers access to view their health information and facilitate greater involvement in their own care. In the United States, more than 19,000 consumers in three states were granted access to their health records in the year-long trial of the Open Notes program. A study on the trial showed that between 60–78% of the 5,391 consumers who accessed their notes and completed a post-intervention survey reported greater medication adherence, compared to when they did not have such access.<sup>1</sup>

Giving consumers access to their own health information also has the potential to identify and prevent certain types of harm not picked up through standard incident monitoring processes. For example, a 2003 study of 228 patients in a Boston teaching hospital identified 20 adverse events and 13 near-misses picked up by the consumers themselves, of which only 11 adverse events and four near-misses were documented in the medical record, while none were reported in the hospital incident management system.<sup>2</sup> In Denmark, one of the first countries to provide consumers with the ability to access their EHR, the National Board for Health implemented a national patient safety reporting database open to medical professionals and the public.

Access to personal health information can enable consumers proactively to monitor their records, and potentially contribute to reducing adverse events. EHRs and clinical information systems can also alert providers to safety issues and incidents.

There is also evidence that new patient safety risks can develop through EHR implementation in a small number of cases. For this reason, the Commission has been appointed to provide clinical safety governance and review for the PCEHR. The Commission has convened

and expert group of consumer, clinical and safety leaders to advise on potential safety issues for the PCEHR. The Commission conducts two PCEHR safety audits annually and can investigate PCEHR-related clinical incidents.

The reliance on the hardware and software driving large healthcare IT systems creates potentially significant points of failure, unless robust backup and fallback procedures are in place. In most healthcare settings, and particularly in hospitals, multiple information systems drive the hospital workflow. These include the patient master index, scheduling and administrative systems, laboratory and imaging systems, and in some cases electronic medical records. Each connected system, or “interface”, can create a potential point of failure that could lead to disruptions in hospital functions and workflow.

Research has also identified safety concerns arising from the interaction between non-technical dimensions of healthcare (workflow, policies and personnel) and the technical dimensions (software, hardware, content and user interface).<sup>3</sup> Patient safety issues can occur when one or more of these technical dimensions interact unexpectedly with non-technical dimensions such as workflow, personnel or existing organisational policies.

For example, a change in the way one system presents information to a clinician may lead to an incorrect interpretation of that clinical information, if the clinician were unaware of that change.

Health IT clinical safety issues are tracked in different ways around the country. Some organisations manage them via their IT help desk; others use their clinical safety reporting systems. The best method of managing health



IT safety issues is not yet clear. What is clear, however, is that there should be a process for managing health IT clinical safety matters if and when they do arise. It is also important to continue to research this emerging field.

In Australia, teams led by Johanna Westbrook and Enrico Coiera from the University of New South Wales (UNSW) are actively researching the safety of EMM systems, and health IT systems more generally.

The Commission has also been active in e-health safety, publishing a Self Evaluation Toolkit to support implementation of electronic discharge summary (eDS) systems in Australian

hospitals, and a guide to the safe implementation of EMMs. These guides were recommended by Health Ministers for use in Australian hospitals.

The Commission supports the incorporation of robust e-health systems into healthcare, and is committed to ensuring that patient safety remains at the core of these systems.

*Prashan Malalasekera is the Project Manager, eHealth and Medication Safety at the Australian Commission for Safety and Quality in Healthcare. In this role, he manages the Commission's Personally Controlled Electronic Health Record Clinical Safety Program. Previously he worked for four years with the National*

*e-Health Transition Authority as a Senior Policy Advisor. He has also worked in operational and project management roles with the Cancer Institute NSW and with the United Nations Development Program overseas.*

- 1 Delbanco et al, "Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead" *Ann Intern Med.* 2012 157(7)
- 2 Weingart et al, "What can hospitalized patients tell us about adverse events? Learning from Patient Reported Incidents" *J Gen Intern Med* (2005) 20
- 3 For example, see Meeks et al, "An analysis of electronic health record-related patient safety concerns", *J Am Med Inform Assoc* 2014 (0) 1



## Remember the vital allies of good healthcare

### Lin Oke

The promise of the Personally Controlled Electronic Health Record to allow consumers' eHealth records to be shared between clinicians, between settings and between various clinical information and management systems is far from being achieved – unfortunately it is increasingly developing into an online medical record rather than a tool for multidisciplinary care and collaboration.

It is essential for quality consumer care that allied health professionals are able to input key findings into the PCEHR to share with the consumer's other treating clinicians. This should be possible from various allied healthcare settings, from hospitals through to community health services. This lack of "horizontal integration" of consumer care is a significant barrier towards meeting the goal of multidisciplinary care and collaboration.

In a report to support Australia's First National Primary Healthcare Strategy it is stated that "A strong culture of multidisciplinary care is seen as critical

to improving the primary healthcare of Australia."<sup>1</sup>

Multidisciplinary care occurs when professionals from a range of disciplines with different but complementary skills, knowledge and experience work together to deliver comprehensive healthcare aimed at providing the best possible outcome for the physical and psychosocial needs of a patient and their carers.<sup>2</sup> Sharing of key information and findings is essential for quality healthcare. It is also far more efficient for the health consumer who does not have to repeat the same information time and again to whomever of the treating team they are seeing.

Allied Health Professions Australia (AHPA) represents more than 80,000 allied health practitioners, many of whom work in primary care, either within, or in close collaboration with, general practices. AHPA has been advocating for allied health input into the PCEHR ever since it was mooted.

Allied health professionals provide services to many consumers with chronic conditions identified as major national health priorities and work

collaboratively with consumers and their medical and health practitioners to assist them regain and maintain good health and prevent hospital re-admissions. Allied health services are a vital component of best practice multidisciplinary care for chronic illness. Such contributions, if recorded via events summaries and specialist letters within the PCEHR, would be of substantial benefit to other health providers and most of all to the consumer themselves.

It is currently not possible for most allied health practitioners to provide input to the PCEHR due to both the limited number of compliant software packages suited to allied health professionals and the prohibitive costs of such software packages for small allied health professional practices. There are no incentive payments provided to allied health professionals to acquire suitable software and to input into the PCEHR as there are to GPs.

The recent PCEHR Panel made 38 recommendations for improving the utilisation of the PCEHR. Just one refers to allied health: No 37 "Commission a

scoping project to identify the options available to encourage further take up of electronic transmission of data by specialist medical and allied health professional practices and private hospitals”.

In order to achieve best practice multidisciplinary care, allied health practitioners must have the ability to upload event summaries and specialist letters to the PCEHR via the provider portal. The beauty of uploading via the provider portal is that it is not dependent on medical software on desktop computers. It accommodates the mobility of the allied health workforce in primary care where many allied practitioners work – across different general practices or in the consumer’s home or residential setting, work place, school or early intervention setting. In rural and remote communities allied health professionals are often ‘out on the road’ for a whole day visiting various consumers. As long as there is internet coverage they can access the PCEHR provider portal. Why not provide health providers the opportunity to input into the PCEHR via the portal – as well as read from it? Opening the provider portal to input from allied health professionals would be a significant contribution to rural and remote consumer healthcare – as well as for those in urban and metropolitan settings.

Enabling allied health practitioners to formally record their contributions through the provider portal would substantially benefit consumers and their other health providers, and save considerable follow-up costs. The current PCEHR system does not support best-practice multidisciplinary care. AHPA believes the uploading option is the most cost-effective and efficient solution for quality consumer eHealth records.

*Lin Oke is the Executive Officer of Allied Health Professions Australia. She qualified as an occupational therapist and neurophysiologist. She has worked in rural hospitals, disability and rehabilitation services, tertiary teaching, association management and a large paediatric hospital where she successfully sought funding for trialling telehealth technologies. Lin has a personal interest in working for better Indigenous health in Australia.*



Photo courtesy of Allied Health Professions Australia

## Allied Health Professions Australia

### Member Organisations

Audiology Australia	Exercise and Sports Science Australia
Australasian Podiatry Council	Occupational Therapy Australia
Australasian Society of Genetic Counsellors	Orthoptics Australia
Australasian Sonographers Association	Osteopathy Australia
Australian Association of Social Workers	Society of Hospital Pharmacists of Australia
Australian Music Therapy Association	Speech Pathology Australia
Australian Orthotic Prosthetic Association	AFFILIATES
Australian Physiotherapy Association	Australian Diabetes Educators Association
Australian Psychological Society	Australian Association of Practice Managers
Australian and New Zealand College of Perfusionists	Diversional Therapy Australia
Chiropractor’s Association of Australia	Hearing Aid Audiometrist Society of Australia
Dietitians Association of Australia	

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# Great expectations – now we need the will

## Mary Potter

The electronic management of health information started out with high hopes by consumers, particularly those with chronic conditions and the elderly. It was to revolutionise healthcare. Just where are those hopes now?

There have been great strides in many areas but the shining white knight of personal health information being readily accessible at any time and any place has not yet been realised. Registered consumers are disappointed they can attend a public hospital and not be asked if they have a PCEHR. Consumers read comments in the press from spokespeople for different medical groups, but on the whole do not understand the issues underlying why their GP, specialist, or hospital are not making better use of this health record.

Although it is commonplace to talk of older people needing and using more healthcare, in reality, older people are not homogeneous and cannot be labelled and defined by chronological age. Whether they are frail aged or active “young” aged, such as the “grey nomad”, they need a well-functioning electronic health record.

People with chronic illness, and this will include many who have developed it later in life, tend to see a number of clinicians, allied health providers, take more medications, and have more frequent hospitalisations, public and private. Consumers want all those involved to “talk” to each other, and have up to date medical records, medications and test results. If the consumer wants to look at any or all of these records, they must be available. The consumer is an integral partner in the process.

However, it doesn't stop there. Many older people and those with chronic illness also use more community services. There is a growing trend

worldwide to integrate health and social services, recognising the strong interconnection between the two.

This appears to be so far an untapped role for the PCEHR. So consumers are registering for the PCEHR — nearly two million have done so at time of writing, despite, with some notable exceptions, little encouragement from their GP.

There is an increasing use of telehealth to monitor patients in the home, and the Department of Health has been running a number of Telehealth Pilots to develop and deliver telehealth services to high speed broadband-enabled homes with a focus on aged care, palliative or cancer care services.

There are a number of advantages to this increased adoption of telehealth:

- health services, particularly specialist care, can become more accessible in regional, rural, remote and outer metropolitan areas
- the difficulties of limited available transport will be minimised
- a reduction in unnecessary hospitalisation may be achieved
- communication during health emergencies could be improved
- there may be the added benefit of reducing social isolation

**CHALLENGE:** eHealth depends on a fast broadband connection, or at the least, a 4G connection.

Other factors are the cost of devices and the cost and availability of setting up the necessary workforce. There is a need for connection nationally, not isolated silos as at present. Currently only specialists in eligible areas are funded by MBS.

eHealth in all its facets is well established within jurisdictions across Australia. A great example is point-of-care pathology testing in rural and remote areas and small metropolitan Emergency Departments that do not have support of 24/7 laboratory onsite.

This enables immediate action on test results, and reduces errors due to deterioration of samples on transport to larger centres. There are challenges such as training of staff and quality control.

Each jurisdiction is designing their eHealth system with capability to connect up nationally with the PCEHR, but currently the connection is seldom happening, although the Northern Territory is actively working on it. The writer (an “active older person”) had a recent experience involving Emergency Departments in public hospitals in two states. X-rays in one city confirmed a diagnosis of an arm fracture. Sixteen hours later in her home state, X-rays were repeated — involving more radiation, more pain, and more expense for the government. This is a classic case of the illustration used to promote the benefits of the PCEHR, but in this case it did not happen. The PCEHR does not, and will not replace point to point messaging, rather, the Record complements it.

**CHALLENGE:** there is a proliferation of small projects which are operating well in a local area but are not connected nationally. As an example some radiology chains give their patients a card containing a phone number any clinician, not only the referring doctor, can call to obtain results. Authorisation occurs as the patient hands the card to the other clinician. This however demonstrates a systemic weakness — no card, no access. How much safer if available through the PCEHR?

One of the recommendations of the recent Review into the PCEHR was that there should be an opt-out process rather than the current opt-in. At time of writing the recommendation has not yet been adopted. If it is, will the system cope with the change of scale?

One of the unheralded benefits appreciated by many older people is the

opportunity to record the location of their Advanced Care Directive. It would be preferable to actually have direct access to a copy, but this is a beneficial first step.

This article may appear negative in its highlighting of challenges. The purpose is quite contrary. The issue may be that the PCEHR was launched with hyperbole as to what it would deliver for all stakeholders, raising unrealisable expectations. Any project the size of the PCEHR will be evolving over time. The technical difficulties of compatible systems and software across practices and jurisdictions were anticipated. It was always planned to have a gradual

roll-out of different elements of the Record, but it appears to be slower than planned. The possible distrust of consumers and clinicians must be addressed, along with the ethos of clinicians at every level.

When there is a will by all concerned to deal with the challenges, then consumers, clinicians, the private sector and government will all greatly benefit.

*Mary Potter is an experienced consumer representative with an interest in e-health and continuity of care. She is currently deputy chair of the Independent Advisory Council for the PCEHR.*

## Making a difference in the NT by ensuring important health information follows the patient



### **Robert Whitehead**

*My eHealth Record*, the Northern Territory's pioneering eHealth system has been in use for over nine years.

The beginnings of *My eHealth Record* can be traced to 2002 and the development of a shared electronic health record in the Northern Territory as part of the Australian Government HealthConnect Trial.

The *My eHealth Record* service built on the strong partnerships formed during the trial between the major Aboriginal Community Controlled Health Services in Katherine, the Katherine Hospital, Indigenous elders and communities, the NT Department of Health and the Australian Government Department of Health.

The *My eHealth Record* service covers mainly Indigenous populations living in rural and remote communities outside the major centres of Darwin and Alice Springs in the Northern Territory.

They are highly mobile and suffer a significantly higher rate of disease than non-indigenous Australians, frequently using multiple primary healthcare

providers in non-government and government sectors, and moving between primary care and hospital services and across State and Territory borders.

The success of *My eHealth Record* is evident in its uptake and use. Over the past four years, consumer registrations have grown by 15 per cent a year, with the total number of registrations increasing from 37,000 at 30 June 2010 to 65,000 at 30 June 2014. This growth was largely driven by clinicians through the use of an eRegistration tool incorporated into their local clinical information system.

Over the same period, clinicians viewing data jumped from 3,300 views per month to 51,700 and the number of clinical documents uploaded rose from 51,000 documents a month to 168,900. Currently, more than 1,200 clinicians access *My eHealth Record* each month.

### *What is My eHealth Record?*

*My eHealth Record* maintains a single secure electronic health record for each registered consumer stored in a central repository accessible via

the internet using a secure portal by authorised clinicians. *My eHealth Record* is integrated into the clinician's desktop computer application and can be accessed by clicking on the *My eHealth Record* icon.

Within a couple of clicks the clinician is able to access information about recent healthcare events or an overview of the consumer's health status.

*My eHealth Record* does not replace the consumer's medical record maintained by their healthcare provider who provides a summary of important information to the consumer's *My eHealth Record*, ensuring quick and easy access by other providers.

### Privacy and Security

Under *My eHealth Record*'s consent model agreed through extensive consultation with consumers and providers in 2004, consumers exercise control in a number of ways. When registering, consumers consent to their health information being sent to *My eHealth Record* and accessed by participating healthcare providers unless they say 'no'.



If a consumer does not want information to be sent or accessed, the consumer only needs to tell the healthcare provider. The consumer can also ask later to prevent access to a summary of a particular healthcare event. Whilst the clinician has a responsibility to advise a consumer about the consequences of information not being accessible, the consumer has the final say.

Consumers are also able to review who has sent or accessed information in their *My eHealth Record* and request corrections.

### What do consumers think of *My eHealth Record*?

Indigenous consumers have enthusiastically embraced *My eHealth Record* and understand their health story is readily available at different healthcare providers. As an older woman told a community meeting, “If I had had the *My eHealth Record* when I went to the hospital last weekend, that nurse would not have been cheeky (disrespectful) to me when I could not remember the tablets I was taking.”

In external evaluation in 2008, consumers rated the registration process as valuing the culturally appropriate communications that enabled them to understand and to consent to sharing their health record. Consumers also considered that *My eHealth Record* had resulted in improved communications between themselves and health centre staff as it reduced difficulties due to language barriers. They felt better able to manage their own health and trusted health professionals to share their health information.

It is very empowering for a consumer with English as a second or third language to be able to say to a health professional, ‘look in the computer’ when being asked for information about diagnoses and medication.

### What do clinicians think of the *My eHealth Record*?

In April 2008, Stephanie Bell, then CEO of the Central Australian Aboriginal Congress said at the launch of *My eHealth Record* in Central Australia, “At times, it has taken so long to obtain the information we need that the patient has become fed up with waiting and



Photos courtesy of Robert Whitehead

has left. This can become a major issue for us, particularly if we discover that the client who has taken off is in urgent need of medication”.

Clinicians support *My eHealth Record* for enabling safer, more coordinated and holistic healthcare and facilitating 24/7 access to key clinical information. It has helped avoid adverse events and to reduce duplication of diagnostic tests and prescriptions, and cut down on ‘red tape’ enabling more timely care and more time with patients rather than chasing information.

### The future?

In July 2012, the Australian Government commenced the rollout of the national Personally Controlled Electronic Health Record system (PCEHR).

The national eHealth record has the potential to significantly improve continuity of care and increase safety of health services. We have already seen examples of this. In recent months an older gentleman presented at an after-hours GP practice in Darwin with multiple medical conditions after having recently returned from interstate for

management of a significant active problem.

He said he was registered with “the national system”. The GP clicked on the national eHealth record and within seconds a full description of his active condition, past history, in-hospital management interstate and recommended post-discharge care was listed with clarity and detail.

This information helped the GP to respond to the patient’s immediate needs and support his ongoing integrated multi-disciplinary healthcare needs. That’s a story we will hear a lot more of as the national eHealth record grows.

*Robert Whitehead is Director, eHealth Policy and Strategy with NT Health. He has an interest in health and privacy law, and commenced providing policy advice to NT Health’s eHealth program in 2004. He has also participated in a number of national eHealth working groups relating to the design and implementation of the healthcare identifiers service and the Personally Controlled Electronic Health Record system.*



# eHealth—growing pains on the journey to digital maturity



## Lisa Pettigrew

eHealth has become synonymous with health. So closely tied is the use of technology to the delivery of healthcare services, that to consider eHealth separately is outdated. However, along with most other industries, eHealth is experiencing growing pains as it reaches towards digital adulthood.

For Australia, as it seeks to forge a path towards better care and world-leading practice, here are six essential eHealth considerations:

### 1. It's all about care – eHealth technology must fill the gaps left by the health system

Lessons from recent years teach us that using technology to reinvent how clinicians work is mostly a fruitless endeavour to which numerous eHealth leaders can attest. Instead, to be relevant, eHealth technology must *fill the gaps* left by the health system.

eHealth technology can usefully support healthcare system navigation, social and community support, integration and coordination for consumers. Technology must offer the integrated care services rarely offered in a consistent manner by any healthcare system, despite clinicians' best intentions.

Truly integrated care can be underpinned by care logistics, which allows seamless referrals, provides helpful reminders and tips, integrates wearable devices for tracking health and wellness data, offers social networks for consumer support, and more — services that are not routinely provided in the fee-for-service world.

### 2. Health is a service and patients are customers – get used to it

Healthcare is a service industry and, just like any service industry, some geographic markets have more choice than others. Technology is the means to make information about those choices available. In fact, technology is fundamental to healthcare as a service, supporting service delivery with less friction than legislation, policy or financial initiatives.

As science improves, diagnoses come earlier and we all live longer. Increasingly, we have to make choices about care. Technology is essential in making consumers informed purchasers of care, and in allowing them to better understand the care decisions made by themselves and their clinicians.

The increasing prevalence and rising cost of chronic conditions means that face to face care may need to be replaced by less expensive approaches. For instance, telehealth and telemedicine may be as effective, or more effective and convenient, than traditional care.

### 3. Liberate the data — eHealth should be the platform for better care

Major government eHealth programs such Australia's Personally Controlled Electronic Health Record (PCEHR) need to become innovation platforms. Government does not need to deliver all services. Government's role is to stimulate investment and activity to drive better care and innovation.

eHealth technologies can easily manage complex consent, privacy and access provisions, which respect the expectations of all health consumers.

Government must assure quality, privacy and security of data held in an accessible form by the PCEHR system. Government should liberate the data to provide opportunities for researchers and technology contributors to develop better tools and services for providing care.

The PCEHR as an innovation platform would encourage and attract new companies with new services that can improve healthcare. Direct-to-consumer companies provide an example of clever technology. Coupled with patient engagement, and sophisticated consent and de-identification models, they offer improved care, *as defined by the patient*.

### 4. Solve the interoperability problem securely and conveniently

Much recent focus has been on implementing enterprise-wide medical record systems, focused on the needs of clinical staff. These systems are foundational elements for any eHealth ecosystem. However, so far, interoperability has not been the priority it needs to be.

Interoperability is essential to enable improvements in healthcare, allowing clinicians to collaborate across organisational and geographic borders, and with each other and patients. The issue with interoperability is the assumption that it already exists – it doesn't.

A crucial challenge is the need for robust security protection. As eHealth connectivity broadens, so too does the opportunity for cybersecurity breaches. A further challenge is never to sacrifice convenience for security.

## 5. There is no grand solution for clinicians and patients

Much debate in recent years has been about how much of the “medical record” should be shared with patients. The presumption being that the record is owned by the clinician. Have we been asking the wrong question all along? Perhaps we should stop seeking a grand eHealth solution for both clinicians and patients.

When booking flights online, we provide information about ourselves and access a great deal of information about airlines. But the airlines also hold significantly more information about the flights than we need to know.

In healthcare, perhaps we should stop aiming to share the same records. Rather, just like airlines, clinicians need certain ‘views’ of healthcare data and patients need different ‘views’. But the systems don’t need to be the same.

Healthcare is complex and special in a way that air travel is not. However, we can learn from other industries more rapidly than from our own attempts.

## 6. Adopt a retailer / wholesaler channel strategy for the PCEHR

The next evolution of the PCEHR should move beyond a government-owned system, to becoming part of the wider healthcare fabric.

The PCEHR must serve the entire public and private healthcare landscape. A first step would be to define the most suitable and secure ways by which consumers can access their PCEHR and give access to others whom they trust.

Consider the PCEHR as a ‘wholesale’ service, which can then be accessed by approved ‘retailers’. Appropriate retailers would be healthcare related organisations with already identified and consented relationships with consumers – for example, health insurers, private hospitals and public health systems.

‘Retailers’ could add value and convenience to the PCEHR by tailoring portals and other access methods to meet the needs of the consumers.

One size does not fit all. Opening up the PCEHR and accrediting multiple secure and convenient access methods would encourage take-up and understanding of eHealth.

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# Should we stripmine your eHealth data?

## **Bruce Baer Arnold and Wendy Bonython**

The development of eHealth in Australia is raising the issue of just who owns the data generated by population-wide health systems. Should Australia be moving towards sale to drug companies, insurers and other businesses of whole-of-population health data, such as weakly de-identified hospital records covering everyone in a state’s public health system? Developments overseas suggest that we need an informed community discussion about potential benefits and harms, looking beyond the current controversy about the PCEHR e-health mega-project.

More than a hundred years ago, two hard-headed US jurists characterised privacy as a right to be left alone, a freedom from inappropriate interference with private life and personal space, extending to respect for individual choices. Such autonomy is fundamental to the dignity of all Australians and a foundation of the contemporary healthcare system.

Characterisation of privacy as freedom from interference encompasses physical integrity and restrictions on inappropriate surveillance, surveillance that in 2014 may involve databases rather than peeping toms and potentially results in people being abstracted as a set of medical

syndromes or health attributes rather than as individuals.

Privacy has been recognised in a succession of international agreements that have been signed by Australia. However, as illustrated in a major report by the Australian Law Reform Commission earlier this year, the protection of private life remains inconsistent and often weak. There’s no comprehensive right to privacy and, indeed, the word ‘privacy’ is missing from the national constitution. We thus have uncertain legal protection in the emerging age of ‘big data’, where health data is seen as a resource that can be commercialised and even strip-mined.

That uncertainty is one reason why we should look at overseas developments, where there is growing controversy about the sale of whole-of-population health records. That sale is being promoted as likely to result in research breakthroughs and efficiencies in public health administration, in addition to providing substantial payments to governments and corporate health service providers for exclusive access to data from millions of people over a period of 20 years or longer.

The salient examples come from the UK. The past year has seen a succession of disclosures that hospital incident records have been sold – and sold very cheaply – by health system administrators to representatives of the insurance, pharmaceutical and marketing industries. The data was in digital formats. It covered much of the English population over more than ten years. The sellers sought to justify the sale by explaining that the data was thoroughly de-identified. That explanation was at odds with statements by the buyers, who in industry presentations referred to re-identification. The scope for re-identification – data matching to remove ostensible anonymity – is receiving increasing academic attention and expressions of concern from bodies such as the OECD in connection with updating of the 1997 global guidelines for data protection.

Controversy over sale of hospital data reinforced criticisms of the UK government's *care.data* initiative, which proposed sale to research institutions, pharmaceutical corporations and others of data from all visits to National Health Service clinicians. Amid the sort of hubris common to information technology mega-projects the proponents of *care.data* boasted that the initiative would position the UK at the front of the health resolution and potentially result in breakthroughs regarding Alzheimers, cancer and lifestyle diseases. Critics were damned as selfish or luddites. There was nothing to worry about, said the proponents, because the data repository would be hacker-proof and strict protocols would ensure anonymity. Everyone would benefit from selling the e-health family silver.

Somewhat embarrassingly, clinicians and consumers started to disagree. Civil

society advocates have been asking whether the initiative complies with UK and EU data protection law. Some have questioned the government's understanding of de-identification and re-identification. More challengingly, clinicians, patients and MPs have been asking hard questions about consent. GPs for example are calling for fully-informed opt-in provision of information, criticising both the assumption that everyone will (or should) agree to undergo harvesting of their health data and the barriers that the government has imposed in allowing people to opt-out as a response to the controversy. Some are questioning whether data should be sold to and thence commercially exploited by multinational corporations, which will necessarily gain a more direct benefit than the people whose health has been recorded in the *care.data* files.

The UK government has somewhat grudgingly promised reforms and meanwhile promoted the *100,000 Genomes* initiative – an opt-in genomic database program that is unsurprisingly promoted as likely to result in breakthroughs regarding Alzheimers, cancer and lifestyle disorders.

Elsewhere we have seen formation of an e-health partnership between Merck, the US-based pharmaceuticals giant, and Maccabi Health. Maccabi is a health service provider that covers roughly a third of Israel's population. Merck gets to access de-identified health data regarding more than a million people over a multi-year period, a forerunner of health analytics exercises in the US, EU and even Australia.

From an Australian perspective it is important to recognise that the overseas experience is not just a matter of ministers looking for good news stories and overenthusiastic health or life-sciences technocrats. It reflects disagreement about who 'owns' e-health data: the patient, the clinician, the government or corporate health service provider? It also respects differing perspectives on the nature of consent, respect for privacy and who gains a direct benefit from use of population-scale. What happens if de-identification is ineffective? Would you endorse differential charges for insurance on the basis of data-mining? Should private health service providers be able to discriminate against

consumers who opt-out of data-mining exercises? Are consumers adequately informed about who is analysing data that relates to their lives (but which they do not own) and able to restrict or commodify specific uses? Are they more broadly informed about public policy conundrums and for example in a position to update Australia's incoherent privacy regime rather than let it be driven by policymakers who have avoided meaningful public consultation regarding MyHR?

We need to look beyond the specifics of MyHR and engage with 'ownership' of public health in a way that respects the dignity of all Australians, fosters research, assists clinicians and recognises potential misuses of e-health data. That engagement requires more than a 'for sale' sign and a consultancy or two.

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# Bringing diagnostic reports into the eHealth record

## Geraldine Robertson

Most Australians will understand just how important it is for diagnostic imaging and pathology results to be easily accessible in any eHealth scheme.

The variety of interests involved in this area has resulted in lengthy and detailed discussions involving specialists' groups, the AMA, the Health Department and of course CHF.

Among the issues which have had to be resolved is how to transfer diagnostic pathology and imaging results to patients' personal eHealth records and at what point the patient is able to view results.

A review of the Personally Controlled Electronic Health Record (PCEHR) conducted for the Federal Government late last year resulted in agreement to proceed with the integration of diagnostic imaging and pathology reports into the PCEHR. The proposed model followed work by NEHTA<sup>1</sup>. The Department of Health has established two design working groups for pathology and diagnostic imaging respectively— to provide input into the design and technical solutions enabling these reports to be incorporated into the PCEHR. Their recommendations were assessed and approved by a wide group of stakeholders. CHF has a consumer representative on each working group and a CHF Policy Officer on the larger Stakeholder group. The aim is to complete this work by December 2014.

## What has been agreed so far

Agreement has been reached that most reports will be posted automatically to the patient's PCEHR seven days after being sent to the referring doctor. This will allow the referrer time to consult with the patient should this be necessary. It will also mean that where the referrer has not contacted patients, the patient can access the report

themselves and be proactive in their healthcare.

The steps of the workflow from patient visit, request, test and report to referrer and patient have also been agreed.

There will be no need for the referring doctor or diagnostic provider to give an ATP, Authority to Post (approval for the report to be posted on the patient's PCEHR). That was an important agreement — though not welcomed by some medical interests. Any ATP would introduce unnecessary and complicated impediments to uploading the report. It would create additional administrative work and could delay posting the report, generating added costs to the tax payer and consumer. In 2012-13 more than 80 million items of pathology were reported suggesting any ATP process would be impractical to implement and administer. Worse it would expose patients to harm if reports failed to be posted, re-introducing the risk of consumers being unaware of test results.

Some reports could be excluded and agreeing which items should be on an exclusion list is the next task for the working groups. Should there be any? Current practice in diagnostic imaging is to give patients a copy of their report and images — though there are exceptions where patient anxiety would result. But perhaps this is a case of useful anxiety, as it may prompt the patient to follow up with their health provider themselves. It has been rare for patients to receive a copy of pathology reports, historically I suppose because of the time taken to complete these tests.

The data to be provided has been agreed. This is the basic information (metadata) to be provided in the report. It includes patient name, date of birth, health identifier numbers for individual patients, pathologist organisations, responsible pathologists, date and time of request, the report and much more. This is not as simple as it seems as in

large pathology and imaging practices there are multiple providers.

There are nine 'disciplines' in Pathology: Anatomical, Chemical, Clinical, Forensic, General, Genetic, Haematology, Immunopathology and Microbiology. A pathology request could require testing in several different sections of the laboratory (or even several labs if the first provider cannot offer that service). This can result in delays in providing a complete report. Several interim reports could be posted before a final one. Sometimes final reports themselves are amended. So it is essential that the provider of each itemized test on the request can be identified and contacted if needed.

Diagnostic Imaging uses plain X-ray radiology, computerised tomography (CT), magnetic resonance imaging (MRI), ultrasound and nuclear medicine imaging techniques to obtain images. Other Interventional radiology treats, as well as diagnoses, disease using imaging equipment and may sub-specialise further so that they only treat abnormalities of the brain or spinal cord or of blood vessels elsewhere in the body.

Providing this detail shows the hidden complexities in deciding the data to provide. It demonstrates the fine detail the working groups have to tease out and agree upon.

Patients will have the option to request their report be withheld from the PCEHR. They can change their mind later. This has also been agreed.

## Safety issues

There are safety issues to be considered such as in the presentation of pathology reports. Where patients have had the same test/s performed by one provider, results for any earlier tests are provided alongside the latest one. This is valuable as it leads to rich information and better monitoring of patients' health, progress (or not) of disease and better care. But, as yet, there is no standard for



pathology reporting and terminology and thus different providers can provide results in different formats. A simple example to explain this is seen with blood tests where one provider presents the latest results in the left column, others on the right. This means clinicians need to be aware of these differences and read the data in date order. This will be an even trickier issue for consumers. Luckily the Royal Australian College of Pathologists' Pitus Project is developing standards and guidelines and these are nearing agreement.<sup>2</sup>

With diagnostic imaging, the need to access previous images also involves safety and quality issues. Where radiologists have access to previous images of the same test, the accuracy of interpretation is greatly enhanced. Diagnostic imaging tests result in an image and a report. Only the report will be posted to the PCEHR (there are many reasons for this including the size of the data and storage requirements). Thus it is extremely important that the location of any image is provided in the metadata. It is also important that

there is a sharing of images between DI providers. This has yet to be agreed and managed.

How previous images can be accessed is a key issue for DI and the PCEHR. So in the meantime it is important for patients to get copies of their images and to provide them themselves when they visit Diagnostic Imaging Practices and their healthcare providers.

Few requests today are ordered electronically. Manual requesting can result in transcription errors and delays. A standard electronic (and manual) request form is needed to improve safety, workflow and efficiency.

Much has been achieved to allow uploading of diagnostic imaging and pathology reports to the PCEHR in December. However the execution has to be seamless and effortless for everyone, including consumers. This means the development of technology that works and encourages health providers to sign up for and use the PCEHR. This is a huge next step. It must not be rushed.

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- 1 National eHealth Transition Authority
- 2 Pathology Information Terminology Units Standardisation (PITUS) Project, the Royal College of Pathologists of Australasia (RCPA) is currently inviting public comment on the Standards and Guidelines, terminology reference sets and preferred units of measure developed for the project. The documents are the result of around 12 months' work from some 70 pathologists, General Practitioners, other clinicians, scientists and informaticians.

## Consumers can control their health and privacy –through eHealth

### Emma Hossack

***“...safeguarding of patient privacy and the reduction of medical error have emerged as the dominant health law issues...privacy and medical error have left the cosy world of professional journals and political platitudes to demand corrective action.”***

Eight years ago I asked the question “How can a shared record be privacy compliant?” The answer surprised me. Research and direct experience with implementations of shared records in communities around Australia, demonstrated that without electronic records it is very difficult for consumers to manage their health information – let alone be in control of who sees what, where and why. The flow of relevant health information improves

co-ordination of care and outcomes.<sup>2</sup>

When information is blocked by people who are afraid of breaching privacy legislation, the results can be fatal. The Caldicott Report<sup>3</sup> in the UK provides many examples of uninformed behaviour which prevented the sharing of critical information leading to tragic outcomes including avoidable death. Privacy is the enabler of ehealth because it engenders trust and confidence in systems. If people do not trust a system or process they are reluctant to share information and participate, even if they are told it will be good for them.<sup>4</sup>

Having information about your health, just as with your finances, is of little use if you cannot easily access and share that information with providers

who will use the information to assist you. For example, in the paper world, patient's information is held in files of their many providers. Copies can be requested, but it is cumbersome. And because it can be embarrassing to ask for copies, is expensive or appears to be confrontational, many people trust their providers to retain all of their information. An average person may have his or her information on dozens of databases. It is also difficult to transact with paper files<sup>5</sup>, so faxes, photocopiers, couriers and mail are used to distribute these files. None of these methods provide good privacy and none of them leave an audit log of who looked at what and from where. In other words in a complex area like health, paper files are neither useful for transactions nor privacy compliant.





Enter the shared electronic health record which began in earnest in Australia when the then Health Minister, Tony Abbott, funded HealthConnect nearly 10 years ago.

Almost 10 years ago Tony Abbott, then Health Minister, made funding available which resulted in the development of Northern Territory shared health record<sup>6</sup> as well as the Extensia shared record which is currently used across Australia to help remote, indigenous, aged, chronically ill and disabled people<sup>7</sup>. The *Deloitte eHealth Report of 2008*<sup>8</sup> recommended a federated approach of shared health records be adopted because the “big bang” approach of one size fits all had never worked internationally. The report warned against a “build it and they will come” approach. So far so good.

The *National Health and Hospital Reform Commission* then published its report in 2009<sup>9</sup> which endorsed this approach. This Report famously stated that the implementation should be done with incentives and that **the government should not be involved with designing, buying or operating IT systems**. As it turns out a very astute recommendation. Unfortunately despite the Government endorsing both reports, they followed neither.

The Health Minister Roxon then said: “I can confirm that the Government is not going to build a massive data repository. We don’t believe it would deliver any additional benefits to clinicians or patients – and it creates unnecessary risks.”

It appeared a sensible approach was being taken. What happened was the opposite.

A large one size fits all repository **was** built and is operated by the Government at a reported cost of \$1 billion, \$500 million over budget. People have failed to come, despite over \$50M used to assist consumer registration. If something is not seen as useful and is not trusted, it fails.

The current government called for a review of the Personally Controlled Electronic Health Record and the Royle Report<sup>10</sup> came back with 38 recommendations. One recommendation suggests a change to the current “opt-in” registration to “opt-out”. What this means is that people would need to make an effort NOT to be registered, because they would be registered by default. We all know that having to act is less appealing than status quo,<sup>11</sup> so registrations would go up. But having more people



registered to something which they are not clamouring for — such as an iPhone 6 for example — ignores the fundamental business case.

If the Personally Controlled Electronic Health Record was easy to use, afforded consumers and their providers something useful which they trusted, they would make the effort to register. Positive health outcomes are what is required, and if 80 per cent of the health funding goes to 20 per cent of the people, then concentration on the 20 per cent group and giving them and their carers choice over care options is more appropriate. Opt-out will not fix the fundamental problem which Australia needs to address – co-ordinating care to improve outcomes, patient journey and efficiency.

The Royle Report recognises the need for eHealth to be decentralised so that people can choose with whom they share their sensitive health data. Having a federation of customised shared records to suit particular communities gives people flexibility and avoids the creation of a large target for cyber criminals to hack. The personally controlled electronic health record should not be sold as a tool for co-ordinating care or the single source of truth. It is neither. Opt-out will not fix the problem and without a massive education programme for Australians, there is a risk of privacy breaches as people may unwittingly find they have a shared record and feel their trust has been betrayed.

As for the question I asked all those years ago? I have my answer. Shared Electronic Health Records put the consumer back in control of their privacy. But one big record for all Australians is not the answer.

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- 1 Nicholas P. Terry, “An eHealth Diptych: The impact of Privacy Regulation on Medical Error and Malpractice Litigation.” *American Journal of Law & Medicine*, 27 (2001)
- 2 26% reduction of avoidable admissions using electronic shared health record to co-ordinate care in Brisbane North DVA trial <http://www.health.gov.au/internet/main/publishing.nsf/Content/pcd-chronic-coordinated-care-round-2-trials>
- 3 The Caldicott Review – Information: To share or not to share 2013 [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/192572/2900774\\_InfoGovernance\\_accv2.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/192572/2900774_InfoGovernance_accv2.pdf)
- 4 The UK NPFIT programme of shared records cost 16 Billion UK pounds and failed to attract consumers. It has been argued that the PCeHR likewise has failed to attract active registrants <http://www.theaustralian.com.au/technology/sector-calls-for-transparency-and-end-to-mistakes-in-pcehr/story-e6frgaxk-1226720434416>
- 5 Booz Report and Productivity Commission
- 6 My eHealth Record. An acknowledged success with in excess of 50,000 indigenous people registered and actively using the system.
- 7 See footnote 2 above.
- 8 <https://www.deloitte.com/assets/Dcom-Australia/Local%20Assets/Documents/Industries/Inner%20East%20Presentation%20July%202009%20web%20version.pdf>
- 9 A Healthier Future for All Australians Final Report, see recommendation 123 [http://www.health.gov.au/internet/nhhrc/publishing.nsf/content/1AFDEAF1FB76A1D8CA257600000B5BE2/\\$File/Final\\_Report\\_of\\_the%20nhhrc\\_June\\_2009.pdf](http://www.health.gov.au/internet/nhhrc/publishing.nsf/content/1AFDEAF1FB76A1D8CA257600000B5BE2/$File/Final_Report_of_the%20nhhrc_June_2009.pdf)
- 10 <http://www.health.gov.au/internet/main/publishing.nsf/Content/PCEHR-Review>
- 11 Professor Cass Sunstein & Richard Thaler “Nudge: improving decisions about Health, Wealth and Happiness”

# How we can end the disconnect in health



## Shane Solomon

Telstra Health was established in April 2013 and officially launched in October this year, outlining its ambition to become Australia's leading provider of integrated eHealth solutions. During that time one of the most common questions I get asked is 'why does Telstra want to get involved in healthcare?'

The answer is that we've seen what the digital revolution has meant for other industries and we believe that healthcare in Australia could benefit from eHealth and more connected systems that better serves all Australians.

I firmly believe that eHealth solutions can be the game changer that lays the foundation for the health system we need. To date eHealth has remained largely the great promise but never has the time been better for delivery.

Health spend is growing more than twice as fast as our economy to nearly 10% of GDP, from \$120 billion in 2010 to an estimated \$200 billion by 2020. Older populations, chronic disease and clinician shortages are just some of the challenges we face to bring quality healthcare to every Australian across a fragmented system.

There are already many great innovations in traditional health technology solutions, but where we see our role, and how we think eHealth can deliver on the promise, is to integrate them across sectors to solve industry challenges. Telstra Health is about connecting you to your doctor, your doctor to your other providers and having access to care and information where you want, when you want.

Within the hospital setting the efficiencies through technology are already very real. I know because I have experienced them and seen the savings. The strengths of an electronic system are the automating procedures and analytics associated with it. Comparing masses of data very quickly is easier,

essentially in real time, when that data is digital as opposed to written on paper. And if you look at any point of the hospital stay process, there are savings that can be made.

20% of patients aged 65 or older who leave hospital are on average re-admitted within a month. When I was the CEO of the Hong Kong Hospital Authority, I oversaw a system that at 3am every morning would automatically run 14 risk factors against the medical records of all patients aged 65 or over that were discharged the day before and arrange a follow up call from a dedicated call centre at the hospital to check on them. For an average of 1.68 calls per patient discharged and a call time of just under 12 minutes, this system led to a 25% reduction in A&E admissions and the same reduction in unplanned admissions. When you see that two per cent of patients consume up to 40% of hospital resources, a system that can identify and intervene in their care at the right moment, in real time, has huge potential to more efficiently target resources and provide better care.

By connecting this information into the applications used by GPs and nurse care co-ordinators, the home healthcare person needs can be organized quickly and efficiently, so avoiding visits to Emergency Departments or premature entry to residential aged care. Results from the Ontario program show that home health monitoring, combined with remote care coordination, can lead to a 70% reduction in ED visits and 60% reduction in hospitalisations.

A pilot of home health monitoring conducted by Telstra Health in partnership with HCF and Healthways has now connected 1000 homes and is the largest trial of its kind in Australia. The Silver Chain Group, one of Australia's largest and most innovative in-home health and care providers, has also chosen Telstra Health to help it to deliver highly specialist nursing care in

the comfort of a person's own home. The solution will use Telstra Health's new eHealth platform and will enable Silver Chain to more closely monitor the health of patients leaving hospital, intervene to reduce a health condition from deteriorating, and avoid a return to hospital.

We need to remember though that while introducing eHealth channels can be done individually with immediate results, in order to maximise the true benefits of eHealth solutions and significantly change the productivity paradigm, we need to operate outside our silos and embrace collaboration and connection.

We've acquired, licensed and joint ventured with 10 of the most innovative eHealth companies from Australia and around the world to establish the foundations for our eHealth system with capabilities in GP, aged and community care, radiology, pathology, pharmacy, hospital and quality and risk management, but our real strength will come from working with the healthcare industry to connect these capabilities together in a way that delivers them tailored solutions to solve their pain points.

The fragmentation of the system too often overcomes the best intentions of providers to put patients at the centre of what they do. eHealth provides the tools to enable collaboration, change that can deliver benefits to patients from the perspective of their entire dealing within the health system, not just an individual appointment or procedure.

It is common place currently that within one hospital there can be five or six views of patient information, a similar number of patient booking systems and none of them are visible to the other.

For eHealth to succeed though we need collaboration and connection not just within a hospital, but across all settings in the health sector; private practice to hospitals, pharmacy to specialists, radiology and pathology to aged care and across private and public.

In order for that to occur it is not just role of Telstra Health. We know that a connected health system can't be built in isolation, so we are working with trusted partners to offer the industry tailored solutions.

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*Hong Kong Hospital Authority. He has over 30 years of international and national healthcare management expertise. Shane is also chair of the Independent Hospital Pricing Authority (IHPA).*



## What's needed to put eHealth on track

### **Peter Brown**

To reach full potential, modern medicine requires individually integrated care and coordinated services provided through safe and secure communication systems. Unfortunately, there is no such widespread, usable infrastructure in Australia.

In recent years, development of local e-health solutions to healthcare problems has been side-tracked by the costly and limited Personally Controlled eHealth Record project, which addresses only a tiny fraction of the true potential of eHealth technology for personal and public good.

Frustration at the poor implementation and management of the PCEHR system has been expressed in submissions to the recent Royle Review of the PCEHR.

There are concerns that more than \$5 billion in government funding alone has been spent over the past 20 years on misdirected, uncoordinated programs — all without any identifiable progress towards an actual, operational, national eHealth information-sharing service capable of delivering the hoped-for benefits.

The primary aim of any e-health system is to improve outcomes for individual patients, to lift productivity and to address population health issues by enabling the better recording, secure exchange and storage of data between patients and their healthcare providers.

But there is a clear distinction between internationally accepted architectures for e-health infrastructure and the limited utility of the Australian-only PCEHR system.

The World Health Organisation defines eHealth as “the combined use of electronic communication and information technology in the health sector”.

However, instead of a workable infrastructure and set of building blocks, Australia has a cumbersome, essentially static storage system of patients' medical record silos which are still largely paper-based (requiring scanning or data entry), lacks clinical decision-making capabilities and is not designed to support dynamic interactions between members of patient care teams.

Nor is there any capacity to benefit public health and safety through the routine capture and interrogation of clinical data, in terms of “computer smarts” that can alert providers to potential errors, pinpoint trends and identify processes/procedures/practitioners that are failing to meet standards. At the same time, enormous opportunities for better use of existing resources and for new fields of medical research through clinical registries and other innovations are lost.

This lack of a workable national ICT networking infrastructure for health information is very poorly understood — and with good reason, as for several

years now the National E-Health Transition Authority in its presentations to Governments, to the Department of Health, to industry, to clinician groups and consumer groups, has repeatedly asserted that the components they were tasked to deliver, have been delivered.

Spruikers like to compare the PCEHR infrastructure with laying a railway. They claim the tracks are in place, the clinical “language” is in broad use, and many other components have come on-stream. All that's needed now, they say, is to improve usability for clinicians.

CeHA believes this is simply not the case. Through our extensive discussions and analysis, we have concluded there is a dramatic gulf between the rhetoric and the reality of the present uncompleted infrastructure.

Continuing with the rail analogy, we do not want to follow the example of the unfixable national rail “system” with its inconsistent, non-interoperable local silos that have held back efficient freight transportation for over a century.

We suggest that, to continue the rail analogy, e-health still has only some of the tracks standardised so there are different rail gauges; we have specifications for a signalling network, but not a connectable network; many wagons are not compatible; the hauling power of the engines vary; driver and staff training differs; the level crossings may have no lights and serious accidents will occur if traffic increases.



Most importantly, no-one has oversight of the whole network to actually understand the true state of play. No-one knows how long it might take for a viable system to become available; nor how much it will cost.

The lack of a detailed business case (or even a simple one), the lack of infrastructure implementation oversight, the lack of adequate governance and community oversight more broadly, and the lack of an implementation plan have all led to where we are today.

Establishing a viable eHealth network requires operational and managerial expertise that enables quality information exchange to be continuously interoperable to support clinicians and health services around the clock; as well as to serve the needs of researchers, telehealth, and Government agencies.

This creates quite a different demand from the normal, one-off event relationships such as with one's banking transactions (another favoured analogy that doesn't fit).

An eHealth system requires an ongoing, ever changing, recording of personal events on a many-to-many basis, often within the context of several relationships, and often with changing personalities.

When the National e-Health Strategy report by Deloitte was adopted by the Australian Health Ministers' Conference in December 2008, the agreed 10-year plan stated: "It is unlikely that any of this can be achieved unless supported by a governance regime which provides appropriate co-ordination, visibility and oversight of National e-Health work program activities and outcomes."

But this approach was set aside in 2010, when the Federal Government created the PCEHR. From here on, the Government drove the design and development of the national program, contracting NEHTA, consultants and external providers to deliver its vision in a very short, two-year timeframe.

Critically, the PCEHR program overlooked the fact that in Australia, the majority of e-health activity is undertaken in the acute sector, funded by state budgets or private hospital operators.

Governments worldwide have been blindsided by well-marketed IT solutions without really understanding the nature of eHealth operations. Unfortunately, global experience has shown that many of the consultants were actually in the same boat, and so have added far less value than the costs of their contributions.

Consumers, more than any sector involved in healthcare, have a vested interest in creating a viable eHealth network that can help contain costs, improve care and the efficiency of health service delivery.

The PCEHR Review panel has recommended the creation of an independent Australian Commission for e-Health, a body tasked with managing the nation's broader e-health initiatives.

This body should bring all stakeholder groups — including consumers — to the one table for the purpose of developing and operating the eHealth infrastructure.

Good governance, with all stakeholder representatives involved at all stages, will allow a better understanding of problems as they arise, leading to better decision-making and acceptance of agreed solutions across the community.

*Peter Brown is a lymphoma survivor who became involved in advocacy with Cancer Voices, then e-Health when he recognised the challenges were similar to those he had encountered in complex documentation when he worked as a freight forwarder in the import/export sector. He helped develop a collaborative electronic conversion scheme in that sector known as Tradegate Limited. He is the Convenor of the Consumers e-Health Alliance (CeHA).*

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