Submission to The Senate Community Affairs Committee

Enquiry on Personally Controlled Electronic Health Records (Consequential Amendments) Bill 2011 and the Personally Controlled Electronic Health Records Bill 2011.

Authors

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Authors' Background

Tom Bowden is the co-founder and CEO of HealthLink Ltd which provides electronic communications, Secure Message Delivery (SMD) and data security services to more than 9,000 healthcare organisations, enabling the delivery of more than 65 million items of clinical information annually. In the community based sector HealthLink is the largest provider of secure messaging delivery services amongst GPs, specialists, primary care facilities, allied health and private diagnostic services. While most of HealthLink's business is in New Zealand; HealthLink has health information exchange contracts with six Australian state and territory governments for diagnostic services, discharge summaries and referrals. Tom has been involved in a series of international health system comparisons and he has performed consulting assignments for government healthcare agencies in the US, Australia, Canada and Denmark.

Geoffrey Sayer is Head of Operations HealthLink in Australia. HealthLink has been in operation in the Australian market for nine years. As former President of the Australian Medical Software Industry Association (MSIA), Geoffrey has represented industry for two years (2009 – 2011) in numerous vendor engagement processes. He has written and spoken on the progress of the eHealth in Australia from a patient safety, efficiency and effectiveness viewpoint.

Consent for Publication

We are more than happy for this submission to be made available for public review on the Senate website.

Introduction

Improving usefulness and cost-effectiveness of health information technology (eHealth) investment is an attractive policy option for OECD countries whose healthcare expenditure is rising at twice the rate of growth of gross domestic product (GDP). Australia needs to get the best returns it can from its ongoing investment in eHealth in order to gain efficiencies and effectiveness in health and healthcare delivery; and to reduce the spiralling cost-growth.

The questions this submission attempts to answer are:

1. What are the optimal policy options for countries wishing to implement eHealth strategies?
2. How does the Australian PCEHR initiative compare with other strategies being pursued around the world?
3. Bearing in mind that eHealth is a relatively new phenomenon, what has been learned about it internationally?

Use of IT to improve health system efficiency

The broad rationale for improving health system efficiency via IT driven automation was well understood by the early 1990s but given impetus by *"The State and Pattern of Health Information Technology Adoption"* a RAND Corporation (Research and Development Corporation) report in 2005 which stated;

"If most (US) hospitals and doctors' offices adopted HIT, the potential efficiency savings for both inpatient and outpatient care could average over $77 billion per year."

The RAND report legitimised emerging plans to develop and implement nation-scale HIT programmes, most of which focused on the sharing of patient records, in some cases, to the exclusion of all other opportunities for systemic improvement. While perhaps once viewed as a relatively simple technology problem, the complexity of creating shared patient health records systems – generally known as electronic health records (EHRs) is gradually becoming apparent:

"Reaching agreement about eHealth strategies and, even much more so, implementing them has almost everywhere proven to be much more complex and time-consuming than initially anticipated. In addition, the complexity of eHealth as a management challenge has been vastly underestimated."

Karl Stroetmann et al, European Commission, DG Information Society and Media, ICT for Health Unit January 2011

"National eHealth programs rarely unfold as predicted, especially when carefully planned out in advance. Of course, that is because they are complex and unpredictable. But policymakers often persist in thinking that things will go better next time."

Trisha Greenhalgh, Jill Russell, Richard E. Ashcroft, and Wayne Parsons,
Queen Mary University of London, December 2011

What is an Electronic Health Record (EHR)?

An EHR takes a number of forms. However at its core, it is an individual patient's record that is continuously updated with information obtained from multiple individual healthcare providers' (GP, Laboratory, hospital etc) computer systems. Implementing EHR systems has proven very challenging. Despite enormous efforts and budget overruns, very few if any national EHR systems are currently working on a significant scale. Where shared electronic health records are making a contribution to health system efficiency, this typically occurs on a relatively limited basis, often within a large healthcare organisation that uses a single patient record system (for example Kaiser Permanente and Veterans Affairs). EHRs that contain

information from multiple sources are relatively rare and those people building them are often surprised to learn that they have limited usefulness.

"It is increasingly evident that clinicians' enthusiasm for comprehensive electronic health records, which may connect patient data in diverse record systems at hospitals, community services etc., relates to perceived benefits in their immediate surroundings (their day-to-day work processes) rather than to a geographically widespread sharing of detailed patient data."

Karl Stroetmann et al, European Commission, DG Information Society and Media, ICT for Health Unit January 2011

What is the opportunity cost of a fixation on EHRs?

While very large sums of money have been spent on large scale electronic health records projects, a total focus on creating EHR systems has diverted attention from other, potentially less complicated uses of technology. Thus healthcare remains a relatively unsophisticated information technology domain. Instead of seeing a progressive curbing of cost growth and a gradual improvement of service quality across the board, a glaring lack of grass-roots level automation is having a severe and growing impact on both cost and quality of healthcare.

Pressure to determine how to get advantage from HIT investment is mounting rapidly, but insufficient progress is being made to justify the large investments (existing and planned). Confusion created by this impasse is obscuring the search for ways to utilise IT in a manner that actually does improve health system performance on a day-to-day basis. While it is extremely clear that there are enormous benefits to be gained from automating health systems by synchronising patient records, there appear to be equally large obstacles preventing extraction of those benefits.

The present situation is perhaps akin to a group of mining companies knowing the approximate whereabouts of a significant gold deposit 10 kilometres beneath the earth's crust but being unable to form a viable plan

to extract it and resorting to randomly drilling holes in the hope of a successful find.

Irrespective of whether EHR systems can be made useful, we must find better ways of assisting healthcare providers to use IT to improve individual patient care, pursue public healthcare objectives and enable artful secondary use of information. Given the burden that the cost of healthcare is placing on most OECD countries' economies, making progress on solving this challenge this should be a matter of immediate and urgent priority for healthcare policymakers. However healthcare policy makers in most OECD countries appear to be content to hand the task to the IT people, be told that the answer lies over the horizon in the form of a large and expensive EHR system. Then the policy makers settle back and watch the IT consortia "kick the can along the road". This is not creating useful outcomes in many countries.

Australia's Personally Controlled Electronic Health Record (PCEHR) is unfortunately an example of a single focused IT driven effort to create sharable records, undertaken to the exclusion of other objectives. Assuming that Australia continues to develop the PCEHR, what is urgently needed is a dual focus; (i) understanding what the barriers are to creating an EHR and (ii) developing other ways that better information management and information exchange can be harnessed to improve day-to-day delivery of healthcare.

What are the obstacles to EHR development?

Initial efforts to gain efficiency benefits from health system automation have focused specifically upon technical solutions, joining records together, extracting data from records and creating new records. In short, EHR development has been viewed as a purely technical challenge. Perhaps because these efforts have been driven so ardently by technologists, scientists and engineers, they have failed to address the deeper, more

complex socio-technical questions that must be answered in order to attain success when introducing sophisticated technology into a complex environment.

The practice of medicine is indeed one of the most complex endeavours known to man. It uses the newest and cleverest innovations that we can create, yet the principles that underpin it go back 3,000 years; as evidenced by the Hippocratic Oath which is still taken by every graduating doctor. Healthcare delivery is expensive, its practice is the domain of some of the most privileged and distinguished members of our society, the recording of it contains some of the darkest secrets of its citizenry and to believe that it can be significantly improved simply by implementing a 'one size fits all' information technology solution is at best naive.

The first step is probably to learn from the initial attempts that have been made to automate health systems. First, a couple of general observations:

"Undue haste to implement early stage technologies into complex, busy and constantly innovating clinical practice settings can harm patients by creating sets of new errors, diverting scarce professional resources and limited healthcare funds."

Karim Keshavjee et al, Canadian Medical Association Journal April 16, 2010

As younger generations embrace technology, one of the oldest tools in medicine, the doctor's note, is in its infancy of reform.

The Annals of Internal Medicine December 2011

These statements; the first by one of Canada's leading health IT specialists, the second by a leading international medical journal show that the experts know that simplistic solutions designed by technologists alone, are unlikely to solve complex problems that arise in health record sharing. We need to stop approaching this problem like a bull constantly charging at a well-built farm gate.

Better understanding the problem we are trying to solve.

Some of the best analysis of this topic is that undertaken by Professor Trisha Greenhalgh who was employed by University College, London. Professor Greenhalgh and her team were engaged by the UK government to analyse the English National Health Service's (NHS') Summary Care Record Project (SCR) and the HealthSpace' patient portal; the combination of which were an attempt to create a national electronic health record, complete with patient access, very similar to that currently planned for Australia.

The NHS initially attempted to implement a comprehensive shared health record system. However, after years of very public argument and disagreement over a range of issues, the system was scaled back to become a Summary Care Record (SCR). Even the scaled down system has encountered significant problems and deemed a failure by many commentators. Progress has been far from smooth.

The main lessons learned from the attempts to launch a national SCR were spelt out Professor Greenhalgh's widely publicised report.

1. Most patients seen in unscheduled care either have conditions for which the data on the SCR is irrelevant or they are able to provide the data themselves.
2. Clinical staff are generally suspicious of the completeness and accuracy of information they are getting from a shared record. This has created a reluctance to refer to it.
3. The cost of developing and maintaining a national shared record system to a minimum standard of quality and safety is prohibitive.
4. The public have continuing concerns over the privacy of their information and sharing of personal medical data without explicit consent has eroded public trust in the healthcare system.

It is difficult to ascertain whether the Australian health system has learned any of lessons by listening to its UK counterparts. If they haven't, we believe they should do so as it is certain that the same challenges will be encountered. Furthermore, it is not clear that Australia has learnt from the lessons of its own earlier eHealth endeavours. It is almost as if NEHTA is

pushing on regardless, in the honest belief that things are now different, that Australia is different and those lessons from home and abroad are no longer relevant.

When questioned at the Health-e-Nation Conference on March 14th 2011 Secretary for Health Jane Halton agreed with a questioner that there is no document in existence that has analysed Australia's EHR requirements and contrasted them with those of other countries. Ms Halton further stated that *"Each country is different, Australia has a unique set of requirements and the PCEHR system has been designed to accommodate those".*

In our view, Australia's requirements are by no means unique and it is a very bold decision to proceed with implementing an EHR strategy without performing a detailed analysis of earlier Australian initiatives and other countries' efforts.

Internationally, sentiment is moving away from building EHRs

Any up-to-date analysis of recent international efforts to implement EHR systems would reveal a marked shift away from efforts to create nation-scale systems, in favour of much smaller, locally focused initiatives. It is quite clear that the focus is shifting from large centrally driven systems to smaller regionally implemented and driven initiatives operating within centrally-led policy frameworks.

In the United Kingdom, three separate efforts are underway to develop local shared record solutions. In the US the Department for Health and Human Services has put in place an initiative based on providing clinicians with incentives for achieving 'meaningful use', thus encouraging physicians to develop local information systems and to exchange and share health records. A number of smaller countries continue to achieve good results without focusing on creation of national electronic health records systems as their key priority.

We believe that a substantial proportion of the reason for the global shift in approach emanates from work done by the King's Fund (a UK based health

policy think tank), to present an alternative approach to achieving systemic change, in particular a change to the way in which they recommend health regions go about developing healthcare system automation.

The King's Fund advocates consideration of a 'Polysystems' approach for encouraging automation. Polysystems theory is an optimised way in which to change a complex 'system of systems' from one state to another e.g. changing a health system from a non-automated state to an automated state. Developed by Professor Itamar Even-Zohar at Tel Aviv University, Polysystem theory advocates the following approach to achieving systemic change in a complex environment:

- clearly defined, achievable objectives, reviewed regularly
- a minimum set of hard and fast rules/boundaries
- effective incentives and disincentives;
- strong leadership, supported by periodic reviews, informed by commentary and constant feedback and comparisons from all stakeholders.

In other words, clear agreement on what needs to be achieved and plenty of flexibility as to how progress is achieved, with a leadership approach that takes stakeholders down an effective eHealth pathway working together in a collaborative and competitive environment with periodic reviews to make minor adjustments to emphasis and focus.

In increasingly stark contrast to the highly prescriptive, meticulously detailed, strongly regimented health IT transformation plans employed by countries such as Canada and Australia, those countries that employ more collaborative approaches that foster innovation and competition are, over time, achieving far better results.

Specific Issue Responses.

Issue 1. Is the PCEHR the right approach for Australia?

In our view it would be most unwise for Australia to count upon the implementation of the PCEHR going to plan. The PCEHR is a high risk strategy. Similar, centrally directed projects in other countries are not going well and in some cases have been halted.

> *"National eHealth programs rarely unfold as predicted, especially when carefully planned out in advance. Of course, that is because they are complex and unpredictable. But policymakers often persist in thinking that things will go better next time. Their hubris has reached a level that deserves to be researched in its own right."*
>
> **Trisha Greenhalgh, Jill Russell, Richard E. Ashcroft, and Wayne Parsons, Queen Mary University of London, December 2011**

There are also mounting concerns that attempting to roll out a national solution within a very tight timeframe is placing considerable pressure on the sector, forcing the use of 'work-arounds', bypassing the introduction of standards, thereby introducing considerable levels of risk, which may well hold back sustainable eHealth service development for a long time to come.

If the PCEHR does go to plan it will at best provide a solution for a specific set of needs relevant to a small proportion of the population, whereas what would be much more helpful is a general increase in the quality of core clinical information so that when it is exchanged it is more useful and easier to integrate with information from other sources (whether or not as part of a shared health record).

It is deeply concerning that it is not possible to order pathology tests from two competing pathology providers in any Australian city and get the information back from those providers in a similar format or with the information coded using the same coding scheme. This lack of basic compatibility (and complete lack of implementation of existing available

standards) means that it is not possible to reuse pathology information in any standardised manner. It is even difficult to graph this information in a meaningful way to assist in day to day patient care (for example to gauge the effectiveness of a standard treatment regime). This is an appalling indictment. Health authorities have continually refused to address these basic, eminently solvable data incompatibilities, this and similar deficiencies while preferring to focus on larger and more ambitious goals.

Unfortunately, building an electronic health record system without standardised data is somewhat akin to building a temple out of bricks with no straw! (and we all know how that ends up). All of the countries that have succeeded in building useful eHealth systems (and there are a number) have first focused on basic data quality issues within a standards framework. They have made the use of standards mandatory and they have made standards adherence a mandatory requirement within any procurement process, thereby ensuring that all systems that operate within their health sectors are able to share and exchange information on a sustainable basis.

Having long ago solved these core standardisation issues, a number of countries have shown that fundamental improvements (measured by quality of care and cost of care) can readily be achieved by implementing basic electronic systems that enable clinicians to share clinical information with each other at the point of care. Countries that have made significant progress in this area include Denmark, Sweden, Holland and New Zealand.

In our view, the most useful gain that Australia could get is by improving the standardisation of basic patient information so that it can be exchanged by healthcare providers and built into patient's electronic medical records and used to inform treatment plans and decision support systems on a day to day basis in every corner of Australia.

Issue 2. Is NEHTA a good investment for the Australian Taxpayer to continue to support?

In our view NEHTA has to defy its critics and deliver a highly functional, widely used PCEHR by the end of calendar year 2012 in order to justify its ongoing existence. If NEHTA does not get the PCEHR system into place it will spell the continuation of a situation in which basic automation and the ability to exchange information in a manner that benefits day-to-day patient care are still absent from the Australian health system, leaving Australia ten years behind most other OECD countries.

Given the lack of uptake of the Health Identifier Service; problems in achieving widespread implementation of medical terminology for medicines and medical vocabulary; challenges in delivering the National Authentication service for health (NASH) and a total void in terms of implementing existing standards; it will be a significant challenge for NEHTA to create an environment that will result in a tipping point to deliver the PCEHR or even the key foundation pieces. On the current course it is likely that a number of stakeholder groups, including participating doctors and practice system vendors, will ask for substantial financial incentives to guarantee their continued participation. In our view that should not be necessary as a well designed e-Health framework would automatically enjoy the active support of all participants. However the Australian government may have no choice if it wishes to continue with this initiative.

Currently a lack of basic automation is placing an intolerable strain upon healthcare delivery and should be viewed as quite unacceptable by healthcare providers, patients and taxpayers.

An additional problem created by NEHTA is the pressure its own existence places on the health IT workforce. There is a finite pool of health IT professionals working in Australia but a large proportion of those people are currently working for NEHTA on fixed term projects. In order to achieve its objectives, NEHTA is actively recruiting people in competition with the private sector and state health organisations and hospitals for short term contracts (the industry magazine quite frequently carries 4-6 pages of NEHTA job advertisements). This is pushing up recruitment costs and salary

levels to the detriment of the industry as a whole. This is especially bad for the health of an industry that wants to be focused upon longer term innovation and sustainable eHealth activities.

The final problem we see with NEHTA is that all automation effort is currently being channelled into a single initiative; “the PCEHR”. Only one consortium is implementing the PCEHR and a relatively small number of companies and consultants are engaged in that process. Many other organisations, sidelined from having a significant involvement, are ‘sitting on their hands’, meanwhile the sector is baying for improved efficiency and information linkages to support healthcare delivery.

What would seem more logical is to develop a strategy in which as many parties as possible can actively participate, sharing the load and working together to automate the sector. For many parties in the sector it is a case of being told ‘hurry up and wait’ for year after year. Additionally, we are seeing development of a culture of dependence upon government contracts and tenders. To succeed in this endeavour Australia must create a dynamic environment that encourages innovation and initiative, inspiring the building of clever IT systems with sustainable business models, systems that will improve productivity by delivering real and lasting value to the sector.

The Deloitte National E-Health Strategy in 2008 gave the industry great hope with its talk of:

- “Market Driven” projects and solutions
- National infrastructure and standards
- A ten year implementation roadmap: a commitment to communicate, collaborate, consolidate
- Adoption of an incremental and distributed approach to development and implementation of an Individual Electronic Health Record

Issue 3: What are the risks of failed PCEHR Introduction?

One major risk is the opportunity cost to the sector of having spent considerable resources with little to show for it by way of productivity gains or system improvement, but there are other risks as well.

"The scale of most ICT projects and the huge sums of taxpayers' money that have been and are being spent on them, make it crucial for governments to address the issues of benchmarking and of accountability so that lessons can be learned."

Improving Health Sector Efficiency – The Role of Information and Communication Technologies – OECD Health Policy Unit, 2010

There are a number of other risks. One of the key risks is that poorly designed and implemented systems, built and run without adequate levels of stakeholder support could easily diminish patient safety. Some examples of this can be seen around the world, particularly in countries where reliance upon healthcare ICT is growing quickly.

We believe it is particularly important to make the correct strategic decisions and influence the right stakeholder behaviour when new systems are implemented. Once a new system is implemented, there is no going back. Interim systems can create more inefficiency and risk than having no systems at all. It is essential that we make the right decisions at every step.

"Over the next 10 years, more information and communication technology (ICT) will be deployed in the health system than in its entire previous history. Systems will be larger in scope, more complex, and move from regional to national and supranational scale. Yet we are at roughly the same place the aviation industry was in the 1950s with respect to system safety."

Professor Enrico Coiera in "The Dangerous Decade" - Journal of the American Medical Informatics Association November 2011

We believe that design and implementation of HIT systems often creates a 'virtuous circle' in which everything steadily improves or a vicious circle in which everything goes bad.

"A virtuous circle and a vicious circle (also referred to as virtuous cycle and vicious cycle) are economic terms. They refer to a complex series of events that reinforces itself through a feedback loop. A virtuous circle has favorable results, while a vicious circle has detrimental results. A virtuous circle can transform into a vicious circle if eventual negative feedback is ignored."

Wikipaedia

In our view it is essential that the correct decisions are taken as soon as possible. There are really only three potential scenarios: systems that do little and do not count for anything (the status quo), systems that improve healthcare delivery, lift productivity and improve quality of care and systems that harm healthcare delivery and therefore either through ineffectiveness or via mistakes, harm patients.

Summary: Where to From Here?

Faced with mounting evidence of the difficulties in building large, nation scale EHR systems, many countries are taking account of the experiences of their counterparts and are developing their own 'Middle Out' strategies, under which a national strategy and minimal core infrastructure are provided by government and complemented by input from the private sector which offers up solutions that meet the strategy and utilise the core infrastructure. 'Middle Out' strategies are put forward as an approach to health system automation by Professor Enrico Coiera of the Centre for Health Informatics at The University of New South Wales. 'Middle-Out' acknowledges that government and providers have different starting points, goals, and resources and they need to work with each other to make automation work.

Professor Coiera asks *"Do we really need government embedded in the process of IT implementation, something it so clearly and routinely struggles with? Or should government should instead be concentrating upon simplifying policy rules, given that it is policy in which they are expert?"*

While Government has handed responsibility for implementing the EHR to a consortium of contractors, every detail of the PCEHR itself is designed by government. Government is most definitely 'embedded in the process of IT implementation'.

Using a truly 'Middle Out' approach:

Government focuses on explaining health policy and then work with the health IT industry to create a broad approach to supporting government's policy with an information technology plan. Much of the detail of the plan is developed by the IT industry, working within agreed guidelines. Government's role is reduce to focus upon policy setting, establish robust and coherent privacy protection, align incentives with health system priorities, steer and accelerate interoperability efforts and strengthen monitoring and evaluation. Any available funding is put into incentives which are channelled by government through healthcare provider organisations, who after all, understand what they need.

Industry works with government to agree on the detail of the above, in some instances taking full responsibility for aspects of standardisation and interoperability. But industry's core focus is on creating a competitive and collaborative environment, capable of delivering the services needed by the health sector.

Concluding Comments

In our view, it is timely that the current approach is carefully examined and some alternatives evaluated. We are very clear of the benefits that well designed and implemented eHealth systems can bring to patients, healthcare providers and taxpayers and we are very keen to assist in any way that we can.

Disclosure of Interest

Tom Bowden is a student at the Centre for Health Informatics, University of New South Wales. He is studying '*Optimal Government Policy Options for Introduction of eHealth Services'.* Tom's company HealthLink Ltd (of which he is a shareholder and Director) is one of the larger eHealth companies active in Australia. HealthLink is involved in the "Wave One" and "Wave Two" PCEHR activities.

Geoffrey Sayer has no financial interests beyond his employment, he has published widely on this topic and he is the immediate Past President of the Australian Medical Software Association.