22 November 2013

Dear PCEHR Review Panel,

The Personally Controlled e-Health Record status needs to be addressed with some urgency if targeted benefits are to be realised.

We suggest there are two major outstanding problems:

1. LACK OF DUE GOVERNANCE 2. INCOMPLETE FOUNDATIONS

1. LACK OF DUE GOVERNANCE.

The primary aim of any e-health system must be to improve outcomes for individual patients, to achieve servicing productivity and to address population health improvements by enabling the better recording, secure exchange and storage of data between patients and their health service providers.

But the PCEHR program is not yet achieving that goal, nor is it delivering the broader community and productivity benefits needed to sustain a quality healthcare service.

We consider the key issue preventing successful implementation is the failure of the various government agencies to act together and engage the community, both public and private, according to the clear advice to create a separate performance oversighting entity directly representing all relevant interests.

The need for collaboration, and an independent management structure, was clearly set out in the Parliamentary "Health Online" report of 2001 and underscored in subsequent reports underpinning the agreed National e-Health Strategy in 2008.

If we reflect on the conclusions detailed in the strategy, recommended by Deloitte, they now appear as unfortunately prophetic:

"Implementation of the four strategic work streams needs to be undertaken in a tightly co-ordinated and concurrent manner in order to effectively deliver the national e-Health work program. Each work stream is highly dependent upon the success of the others."

After a detailed explanation, the report states:

"It is unlikely that any of this can be achieved unless supported by a governance regime which provides appropriate coordination, visibility and oversight of national e-health work program activities and outcomes."

Many of those involved in the development process remain frustrated that the many arms of our federated governments, whilst having endorsed the obvious validity of this key recommendation, have not actioned it.

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The necessary directions to both HealthConnect and the National e-Health Transition Authority have been lacking or ignored. Thus the subsequent shortcomings have been repeated.

Thus responsible governance necessary for the success of any such organised activity has not been appropriately created. As a result, the essential requirement for suitable business plans including ongoing funding, their skilled management and operational and financial auditing has not occurred, at least not within effective public knowledge.

This has resulted in spending over $1 billion of public funding on the PCEHR, but much much more on e-health overall, in a decade of misdirected, uncoordinated programs without any identifiable progress towards the implementation of a much needed, 85% community supported, National Electronic Health Service.

The existing siloed structure across the entire health system needs to be changed within an integrated network of services but this will require the support of quality electronic communication and recordkeeping infrastructure.

CeHA hopes momentum can be restored to the e-health program by adopting the recommended collaborative governance approach and initially keeping things simple by building on what exists and in a clinical sense is working.

It considers the basic PCEHR system could provide a foundation for a revitalised and effective patient health information-sharing service that is used and trusted by both clinicians and consumers.

We hope to be enabled to work closely with a truly independent National E-Health Governing Council that brings medicos, consumers, the local health IT industry and government agencies together with a unified objective. This council should have oversight of a new entity tasked with implementation and operational responsibilities.

2. INCOMPLETE FOUNDATIONS

There is an important distinction between what is an "e-health" system, and the limited utility of the PCEHR system.

The World Health Organisation defines e-health as "the combined use of electronic communication and information technology in the health sector". Clearly this needs a workable infrastructure and set of building blocks.

Instead of various healthcare components that can now be "delivered, enabled or supported through the use of information and communication technologies", 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.

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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 fields of new medical research are lost, e.g. through clinical registries, etc.

We contend that Australia still lacks a workable national ICT infrastructure - the goal of our Commonwealth, State and Territory Governments since the 1997 Health Online Report - that will deliver an e-health system for the future.

This lack of infrastructure is very poorly understood - and with good reason, as for several years now NEHTA in its presentations to Governments, to the Department of Health, to industry, to clinician groups and consumer groups, has "pretended" that the PCEHR infrastructure is in place. They have repeatedly asserted that the components they were tasked to deliver, have been delivered.

Close inspection of implementations to date suggest otherwise. We certainly don't know, for example, the extent to which the Australian Medicines Terminology has been installed into clinical systems in GP clinics, or hospitals, but it is more likely closer to five single installations, rather than 50,000 installations. Without a common clinical terminology, how are we to achieve the basic, accurate medication list so often and so proudly spruiked as a feature of the PCEHR?

The number of Healthcare Identifiers allocated to individual providers and in active use today is probably more like 5,000 rather than the needed 500,000. And the number of hospitals, public and private, that are routinely processing patients' Individual Healthcare Identifiers can probably be counted on one hand.

There is no adequate national provider directory in place.

There is very little installed capability for secure message delivery to drive the flow of information needed to supply the PCEHR, and permit access to and processing of the information it holds.

Although there is some authentication for the PCEHR services per se, there are no national authentication services for health more broadly.

But even the AMA President was reported recently as suggesting (likening the PCEHR infrastructure to a rail network) that the tracks are now in place, the clinical "language" is in broad use, and many of the other components have come on-stream -- and that now we just need to improve the usability for clinicians.

Well, CeHA believes that this is not the case. Through our extensive discussions and analysis, we have concluded there is a dramatic gulf between the rhetoric and the reality.

Continuing with the rail network analogy, we do not want to follow the example of the unfixable "national rail system" where we continue with inconsistent, non-interoperable silos of local systems that have held back efficient freight transportation for well over a century.

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But we suggest that in e-health, we still have only some of the tracks standardised so rail gauges are different; we have specifications for a signalling network, but not the actual network itself; 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 of all, no-one has oversight of the whole network to actually understand what the true state of play is!

It is no wonder that GPs and patients have little faith in such a system. It appears the gulf between the vision of what the PCEHR could provide, and what it is currently capable of providing, is profound.

Non-standard systems continue to be installed throughout due to lack of direction.

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, reviewing a (reportedly) "shambolic" system.

We strongly advocate for a new direction. For instance, we recommend close collaboration between Medicare Locals in primary care and the Local Hospital Districts for secondary care.

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

Yours Sincerely,

Peter Brown,
for Consumers e-Health Alliance.

Communication | Co-operation | Collaboration | Coordination

Keep It Simple

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