

CeHA - Consumers eHealth Alliance

Jeanette Radcliffe
Secretary,
Standing Committee on Community Affairs, Legislation Committee

30 October 2015

Dear Ms Radcliffe

Inquiry into the Health Legislation Amendment (eHealth) Bill 2015

Thank you for the opportunity to comment on the Bill now before the Senate.

On 28 May 2015, the Department of Health released a discussion paper canvassing these proposed legislative changes for public consultation, and allowed just 19 working days for interested parties to respond.

A small number of limited consultation briefings were held in Sydney, Melbourne, Brisbane and Canberra to introduce the opt-out concept. Further small meetings were held in Sydney and Melbourne to explain the proposed amendment legislation.

Given the time constraint and complexity of the implications, the fact that 137 submissions were received reflects the community's strong concerns. A large number of submissions came from individual citizens, and there was very broad representation from community groups, medical professionals, health service providers, and private industry.

Yet there has been no analysis and no response to the matters raised in these submissions by either the Department or the Government, and the submissions do not appear to have been considered in any way, let alone addressed, in the tabled legislation.

We therefore recommend the Committee considers the discussion paper and the submissions made in response to it.

We attach a copy of our submission¹ and the link to the departmental consultation material² – which is to be found not on the main Health website but on the lesser-known eHealth/PCEHR website.

Further, we would draw the Committee's attention to the Parliamentary Joint Committee on Human Rights report on the proposed bill. The committee's findings and recommendations reflect many of the concerns raised in the public submissions, and the many risks that will flow from a mandatory opt-out system.

1 http://ceha.org.au/wp-content/uploads/2015/07/CeHA_submission_PCEHR_legislation_3.pdf

2 <http://www.ehealth.gov.au/internet/ehealth/publishing.nsf/Content/consultation-submissions>

"The [PJCHR] considers that the bill, in enabling the uploading of everyone's personal health records onto a government database without their consent, engages and limits the right to privacy," the report says.

"It is questionable whether the objective behind the bill, in amending the system to an opt-out model, would be considered a legitimate objective for the purposes of international human rights law. A legitimate objective must address a pressing or substantial concern and not simply seek an outcome regarded as desirable or convenient."

"Increasing the number of people using the My Health Record system, in an attempt to drive increased use by healthcare providers, may be regarded as a desirable or convenient outcome but may not be pressing and substantial enough to warrant limiting the right."

PJCHR chair Philip Ruddock has written to the Minister for Health, Sussan Ley, seeking advice on these important matters. Presumably Ms Ley will respond before the Senate considers the bill.

However, just last Wednesday, at the National Press Club, Ms Ley threw further confusion into the mix by announcing that *"all-inclusive trials of the Government's new My Health Record will commence in early 2016 for around 1 million Australians. The trials will be held in Far North Queensland and in the NSW Nepean Blue Mountains region"*.

Yet the bill enabling the opt-out trials (amid other sensitive issues) is still before the Parliament!

But we do welcome Ms Ley's comments about needing *"a health system where the patient is centre of everything"*, and her enthusiasm for delivering a 21st century healthcare model.

Disappointingly, we are highly unlikely to achieve this if the Government believes rebadging the PCEHR will deliver digital innovation.

The PCEHR was based on a concept whose time was already past when it went live.

Rather than an efficient and trusted means of information exchange, the system resembles a big old filing cabinet, randomly stuffed with a selection of documents that may or may not be current, relevant or accurate.

That is why doctors don't use it, and consumers show little interest either.

Yet we recognise that we do need a well-managed and "light touch" e-health information-sharing network, to support patients and their healthcare across the community.

Ms Ley recently announced an implementation taskforce steering committee to establish the proposed new e-health management body, the Australian Commission for eHealth.

We believe Ms Ley could take this as an opportunity to truly open the door to 21st century healthcare, by examining alternatives to the failed PCEHR approach and designing an e-health system with the patient at the centre.

To do this, the focus needs to be on people, and on effective engagement with clinicians and their patients.

In our submission to the Legislation Amendment paper, we said this legislation is premature, as the Royle Review recommended ACeH should function as an operational entity, governed by a board representing all stakeholders, and with full responsibility for decision-making and planning, supported by active working committees and experienced staff.

But clearly the Department doesn't wish to relinquish control. It appears the future ACeH will absorb the current National E-Health Transition Authority staff and be operated from within the Department itself.

DoH Strategic Health Systems and Information Management special adviser Paul Madden told Senate Estimates in October that the steering committee has begun "to do the design of the new organisation and the planning of the transition of people, functions, skills and resources from NEHTA."

He went on: "But do not see this as moving the function of NEHTA to a new thing. It actually functions from within the Department – the operations of the eHealth system."

Mr Madden indicates there won't be much of an issue over redundancy.

He continues to demonstrate the NEHTA/Departmental view that public consultation is a one-way street. It has to be seen to be done, but the results are always ignored.

Reconstituting NEHTA within the Department in an operational role won't work. It is not what was recommended in the Royle Review, and the responses to that review supported the need for a totally new approach.

In our submission to the Review³, we suggested there were two major outstanding problems: lack of due governance, and incomplete foundations. These issues were addressed by the review, but are not addressed in the amending legislation.

This is how the Royle Report envisaged ACeH⁴:

New Australian Commission for Electronic Health (ACeH)

It is recommended that NEHTA's current overarching role be dissolved and replaced by an Australian Commission for Electronic Health (ACeH) – similar in principle to the Independent Hospital Pricing Authority – established as a Statutory Authority and reporting directly to the Standing Council on Health.

ACeH should have the following key terms of reference:

- Development and execution of eHealth strategies (not just the MyHR) within the policy framework set by the Department of Health in conjunction with the Federal Minister for Health.

³ http://ceha.org.au/wp-content/uploads/2013/11/CeHA_PCEHR_Review_2013_submission.pdf

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[http://www.health.gov.au/internet/main/publishing.nsf/content/17BF043A41D470A9CA257E13000C9322/\\$File/FINAL-Review-of-PCEHR-December-2013.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/17BF043A41D470A9CA257E13000C9322/$File/FINAL-Review-of-PCEHR-December-2013.pdf)

- Setting of implementation and funding priorities for eHealth initiatives.
- Coordination and management of the government funding allocated to the implementation and management of eHealth in Australia.
- Provide and manage a vendor accreditation process to ensure appropriate integration with the MyHR.
- Provision of frameworks and requirements to allow value adding vendors to integrate with the MyHR.
- Monitoring of the performance, adoption and management of eHealth systems, including oversight of the Systems Operator.
- Provide open and transparent communication of the performance of the eHealth system.

Composition of the Board of ACeH must ensure the effective representation and balance of care providers and consumers in the ongoing governance of the system.

The following composition is recommended:

- Independent Chair (nominated by the Federal Minister for Health)
- Federal Department of Health representative
- Jurisdictional representative – nominated by the Australian Health Ministers Advisory Committee (AHMAC)
- Consumer (Nominated by the Consumer Advisory Committee)
- General Practitioner; Medical Specialist; Pharmacist; Registered Nurse or Nurse Practitioner; Allied Health Professional; Private Hospital Operator; Aged Care Operator; Health software industry representative, and Department of Human Services representative (representing the system operator).

The critical selection criteria for nomination to these ACeH Board positions is an active interest and engagement in eHealth. Positions should be advertised and if organisations want to encourage applications from within they can – in order to get the best candidates, and hopefully avoid sectional interests.

Conclusions

1. We are concerned that there has been no analysis and no response to the submissions already provided to the Department of Health on the proposed eHealth Bill.
2. We are concerned that, potentially, this Committee is required to report before Ms Ley responds to the issues raised by the Parliamentary Joint Committee on Human Rights.
3. Planning for the Australian Commission for eHealth does not align with the recommended broad stakeholder foundation, governance and operational arrangements.
4. The reality is, the PCEHR is based on a concept that is already outdated, and won't support the kind of digital innovation the Government is seeking in health.

5. We believe this legislation should be set aside, in favour of a renewed vision for eHealth. We urge the Government to instead lead a new conversation with the nation about digital healthcare in the 21st century.

Recommendations

We urge the Community Affairs Legislation Committee to consider the 137 submissions made in response to the earlier consultation over changes to the eHealth legislation.

We call for reflection on the critical points raised by the PJCHR in respect of the nature and scale of vulnerable people - and the practical and legal difficulties of obtaining proper, informed, consent from an unengaged populace.

We recommend that the planned Opt-Out Trials be delayed until all of the issues raised by the PJCHR are addressed, including how the opt-out process will work, the period of notice for people to respond and their ability to do so, the ability of the System Operator to deem that a person “*has been given the opportunity*” to not be registered, the inability to erase records once uploaded.

As well, serious concerns over the automatic inclusion of children’s health records on the system, along with the automatic inclusion of health records belonging to people with disabilities (and, again, the System Operator’s capacity to deem a person “*not capable of making their own decisions*”) need to be addressed.

We note with alarm that the Bill provides that once the opt-out trials have taken place, the Minister for Health can, by making rules, apply the opt-out model to every Australian. The PJCHR warns: “*There is no requirement that the minister consider the privacy implications of this decision or whether people in the trial were given an appropriate and informed opportunity to opt-out.*”

We recommend that a final decision on any switch from opt-in to opt-out be returned to the Parliament for consideration.

Yours Sincerely,

Peter Brown

Convenor, Consumers e-Health Alliance