CeHA - Consumers eHealth Alliance

July 19, 2015

Submission

Department of Health Legislation Discussion Paper: Electronic Health Records and Health Identifiers

Thank you for this opportunity to respond to the issues raised in this paper, and at the recent consultation sessions.

The Consumers eHealth Alliance considers it premature for the Australian Government to contemplate legislative changes and pilots to test an opt-out national electronic health record-sharing system.

Instead, the priority should be consultation on the formation, composition and operational aspects of the proposed Australian Commission on eHealth, as this new entity should rightfully be tasked with decision-making on future PCEHR/My Health Record (MyHR) developments.

We believe the Department should engage in very broad community consultation with stakeholders, with a view to identifying people with the necessary expertise and bringing them together as a foundation body. We do not believe the Department should try to pick participants, as this approach has failed to date as is evidenced in various related reports.

This legislation is premature because:

1. It precedes consultation and creation of the ACeH structure. The proposed Australian Commission for eHealth (ACeH), as operator of the system, should function as an operational entity, governed by a board with full responsibility for decision-making and planning, supported by active working committees and experienced staff.

The Legislation discussion paper says ACeH "*will assume responsibility for governance of all national eHealth operations and functions*", while the Department "*retains responsibility for national eHealth policy*".

This does not make sense. ACeH clearly should have a lead role in policy-making, as it will have considerable expertise and practical experience within its board (including representatives from the Commonwealth and State and Territory governments), and committees and staff. These people will have to respond to issues and concerns as they arise, so are best placed to find and implement the solutions.

2. The Government is yet to reach agreement with the States and Territories on future plans for a national approach to eHealth. There is a risk some or all States and Territories will not agree with the proposed arrangements.

The Department is refusing to release the *eHealth Working Group (EHWG) National eHealth Strategy for Australia* on the grounds that "*disclosure would pre-empt and potentially undermine the discussion being undertaken in relation to the revised strategy. Given the nature of the issues being discussed, disclosure before a decision by the Council of Australian Governments Health Council is made would damage relations with the States and Territories*".

The draft strategy is a revised version of the *National eHealth Strategy* developed by Deloitte and adopted by COAG in 2008. It is frequently referenced in the Review of the Personally Controlled Electronic Health Record, provided to then-Minister Peter Dutton late in 2013.

The Royle Report supports a key change in governance to enforce broad population participation, by switching from voluntary and opt-in for patients, to mandatory and opt-out for all citizens.

CeHA affiliate Karen Dearne made a Freedom of Information request[1] for the release of the Deloitte EHWG strategy summary report in May, on the grounds that senior Health staff had begun consultations on proposed operational and legal changes to the existing PCEHR system apparently based on the findings and recommendations of the Deloitte working group.

In refusing access to this document, DoH Assistant Secretary, eHealth Policy Branch, acknowledged[2] that "access to the document would inform debate on a matter of public importance".

"*On the other hand there is a public interest in the Commonwealth maintaining good relations with the States and Territories to be able to achieve mutual objectives ....Disclosure would inhibit the ability of the Commonwealth to work closely with the States and Territories on finalising their agreement to a revised National eHealth Strategy.*" We think the contrary is more likely to succeed.

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[1] FOI request https://www.righttoknow.org.au/request/deloitte_ehealth_working_group_n#incoming-3635

[2] FOI refusal https://www.righttoknow.org.au/request/1067/response/3635/attach/3/FOI 258 1415 Signed decision letter D15 721070.PDF.pdf

Given that the 18-page summary document has been available to the Government since October 2013, it seems clear that it has not made much progress with its jurisdictional partners. Each of the States and Territories is proceeding with its own ehealth programs.

Whatever the eventual outcome of discussions with the jurisdictions, it is unrealistic to expect that ACeH could be up and running by July 2016.

We suggest that the nature of the changes required indicates that an ACeH-style advisory group, or steering committee, of all stakeholders should be set up as soon as possible to consider the input necessary to cover all aspects needing attention.

3. CeHA agrees with the Discussion paper's statement, "*Any decision to move to a national opt-out participation model for the PCEHR would be a significant decision and Government would need to examine its ramifications before implementing such a model*" (in conjunction with all key stakeholders).

The Health Department has been tardy in releasing material relevant to this discussion paper - a Deloitte report on *Public consultations into the implementation of the recommendations of the Review of the PCEHR* was quietly released [3] on June 9, while a fresh *Privacy Impact Assessment on the PCEHR System Opt-Out Model* [4] conducted by Minter Ellison was only published on July 2, a full week after the consultation period ended. The PIA was completed on May 15 (see a range of comments from the Minter Ellison report below).

It is hardly conducive to effective consultation to withhold key documents from interested parties. Both documents point to serious problems in switching to an opt-out regime.

CeHA also has concerns with oft-repeated claims that "once consumers have an e-health record explained to them" they are in favour of signing up and, of course, everyone should have one.

Naturally consumers believe having a secure, quality, electronic health record that can be shared among their health providers is a good thing.

The problem, however, is that with the PCEHR they are not getting what they've been led to expect.

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[3] Deloitte public consultations report
http://health.gov.au/internet/main/publishing.nsf/Content/17BF043A41D470A9CA257E13000C9322/$File/Report - Consultation on PCEHR Review Recommendations - Sep2014.pdf

[4] Minter Ellison PIA
http://www.ehealth.gov.au/internet/ehealth/publishing.nsf/Content/21C511E1CC1A6850CA257E7600208E8D/$File/PCEHR%20Opt%20Out%20PIA%20-%202015.pdf

The difficulty lies in the "model" chosen for the PCEHR and perpetuated in the rebranded MyHR.

Rather than a safe, secure, efficient and trusted information exchange supporting collaborative or team care for individual patients, the PCEHR resembles a vast metal filing cabinet somewhere containing a haphazard selection of documents that may or may not be relevant, current, or accurate. By admission it is actually a summary record produced by a limited number of clinicians.

Providers who want to use the system have to pretty much drive out there and have a rummage through, in vague hopes of finding something useful. The system is not searchable.

CeHA explored the reality in *An analysis of Commonwealth Government annual reports covering e-health and PCEHR activities in 2013-14* [5] last year.

We found that after two years and more than $1 billion in costs, only 26,332 shared health summaries had been uploaded by doctors.

However, more than 140 million government documents - MBS, PBS, Veterans Affairs, organ donor and childhood registers - have been stuffed into a system then catering for just 1.7 million Australians.

Only 71,132 records out of a total 140,639,585 records could be considered clinically relevant.

It is unclear how moving to opt-out will improve the quality and usefulness of the records for health providers. The model remains one of an old mainframe, in an era of web and mobile connectivity; the records are static snapshots in time.

However, it is extremely likely the current infrastructure will require a significant upgrade to support the inclusion of 24 million new records. Nor does it provide scope for improved methodologies in the future.

It is worth noting that Accenture, as National Infrastructure Operator, has already been awarded more than $106 million for four years' operation of the system, between July 2012 to June 2016 (roughly $27 million a year).

This is on top of the $109 million paid to Accenture and its partners Oracle and Orion to actually build the infrastructure; it was never designed to support the whole population's health records.

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5 CeHA analysis report http://ceha.org.au/wp-content/uploads/2014/12/AnalysisPCEHR-Final.pdf

4. Discussion of opt-out trials is highly premature, as adoption by providers is nowhere near widespread. Indeed, private and most public hospitals, medical specialists, aged care facilities and allied health providers including physiotherapists, speech pathologists, osteopaths, optometrists, dentists, many pharmacists and pathology/medical imaging centres are not yet capable of uploading or downloading documents from the existing PCEHR system.

It is not possible to test the success or otherwise of an opt-out system where documents are not accessible in the kind of health facilities most citizens would use.

We believe the only trial sites that could be chosen at present are those that have already been part of the PCEHR lead site and wave 2 programs, and are thus not representative of current reality across most of Australia.

Nor will such time-limited trials identify risks from breaches of medical confidentiality (including access to personal records by insurers or employers, or through criminal attacks resulting in misuse of data and fraud), which may take many years to emerge. A six-month trial is ludicrously short, given that many people might not pay a visit to their doctor or clinic during that period.

It is unclear what the Department hopes to prove by this ill-conceived proposal. It will be vastly complex and difficult to co-opt people by geographic location into test groups.

St Vincent's Hospital in Sydney, for example, has we understand been one of the more successful PCEHR trial sites, but the high-density population, often transient, in this inner-east Sydney catchment area make it an unstable and unrepresentative trial site. ("Successful" in so far as we know anecdotally. None of the "learnings" gained through the PCEHR pilots have been shared with the community, nor has there been any reporting of outcomes.)

Another big concern for consumers is plain old snooping. New Zealand's Privacy Commissioner John Edwards recently warned that "*shared electronic health records are potentially available to anyone in the world with the appropriate credentials, can be downloaded almost instantly, and the information on them can be much more easily aggregated into a large dataset*".

"*This allows widespread and damaging accidental or malicious disclosures, and also increases the likelihood that secondary uses will be found, beyond the original purpose for which the information was collected - function creep.*"

Rather than a centralised national system, NZ has developed Shared Care Records, which are maintained within regional health districts. What is being done in other countries?

What standards are proposed? Do we have any now operating after 10 years of the National e-Health Transition Authority (NEHTA)?

The New Zealand SCRs are an online summary of the care record, extracted from GPs' own computerised practice management systems and automatically uploaded for use by local health workers; patients have a right to opt-out, and the systems are protected by strong authentication controls and access audits. There is no provision for secondary use by third parties.

In his report, *Elements of Trust* [6], Mr Edwards notes that in NZ, "*Health professionals accessing a Shared Care Record are considered to be collecting information from a source other than the patient and therefore need either the patient's permission or another good reason to do so (such) as where the patient is unavailable or unable to give consent.*"

CeHA notes that the PCEHR system does not have strong authentication or access audit capabilities, due to the failure to complete the National Authentication Service for Health.

The present Public Key Infrastructure user verification system only captures information about the healthcare organisation accessing someone's record; there is no capacity to identify individual users within organisations who may be accessing records without authorisation to "snoop" on celebrities or people they know. Wrongly, the Minter Ellison PIA suggests there is a working fine-grain access log.

Nor is there any mechanism for improvement of data quality. As Minter Ellison notes, "*Poor data quality from source data can lead to errors within the PCEHR system, including clinical information being attributed to the wrong person, or incorrect clinical information being attributed to the correct person. This can in turn lead to errors in clinical decision-making, with negative health outcomes for the individual, and/or privacy breaches which lead to harms such as discrimination or embarrassment.*"

CeHA awaits with interest the Department of Health's response to Minter Ellison's 46 recommendations on a wide range of issues. Again, we believe it is premature to proceed with legislative changes and opt-out trials until these matters have been satisfactorily addressed.

The Minter Ellison Privacy Impact Assessment says:

"The shift from an opt-in model to an opt-out model is a significant policy change. There is a

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[6] NZ privacy report, Elements of Trust https://www.privacy.org.nz/news-and-publications/reports-to-parliament-and-government/the-privacy-commissioners-electronic-shared-care-records-review-elements-of-trust/

risk that the move will be seen by some in the community as heavy-handed. The fact that the health information to be populated in the PCEHR will include up to two years' retrospective Medicare data may further exacerbate for individuals a sense of loss of autonomy."

"The stakeholders consulted (by Deloitte) on behalf of the Department in relation to this proposed change have raised similar concerns such as: 'Some stakeholders were concerned that this could be seen as a somewhat sinister move to force people into a system that would give Governments and others access to confidential health information which could then be used for unknown purposes'."

"If opt-out does not deliver the critical mass needed to deliver value from the PCEHR system - in terms of health benefits to the individual and improved overall health outcomes, which leads to health system cost saving benefits to the taxpayer - members of the public may perceive themselves as carrying all the risks (individuals with PCEHRs will carry the privacy risks, and taxpayers the financial risks), but without reaping the benefits."

"The draft Deloitte report also found: 'The majority of consumers consulted are unlikely to block access to their record or to particular documents except in very special circumstances (such as ultrasound scan of a dead foetus prior to termination)."

"A risk scenario that arises with implementing an opt-out model is large numbers of individuals asserting that they were unaware of the change and its implications. For example, 'I was never told the government was going to start sharing all my health information; if I had known I never would have agreed to that, and now X person knows I have Y illness'."

"The proposed default privacy control settings mean that the individual who does not act to gain access to their PCEHR and adjust their privacy control settings will receive no notifications, retrospective Medicare data will begin to populate their PCEHR as soon as a healthcare provider either views or uploads to it, and all clinical documents in the PCEHR will be available to all their healthcare providers."

"There is a risk that individuals do not understand that this means, for example: that their physiotherapist, optometrist and dentist can see from their PBS records that they have been prescribed antidepressants; that their boyfriend, who works in a hospital where they were once treated for a broken arm, can see that they have recently terminated a pregnancy in a different hospital; or, that their home address may be included in a clinical document accessible by a person who wishes them harm."

"There is a spectrum of privacy harms which could potentially arise when an individual's health information is exposed to third parties. This spectrum has tangible or 'material' harms at one end (physical harm or threats of violence, stalking and harassment, identity theft, financial loss and psychological damage), intangible or 'moral' harms in the middle

(reputational damage, 'creepy inferences', humiliation, embarrassment or anxiety, loss of autonomy, discrimination and social exclusion), and abstract or 'social' harms at the other end (loss of trust and social cohesion posed by a 'surveillance society')."

"People with legitimate access to a database can sometimes feel tempted to look up the records of people they know personally, or public figures. They might be motivated by curiosity, or by a plan to use any personal information they find for some personal benefit - such as leverage in a dispute with that person, or by selling the information to an interested third party. Authorised users may already know enough details about family members, friends and acquaintances to enable access to their PCEHR. This is an existing risk, managed in a variety of ways. However this risk will be multiplied with the switch to an opt-out model, as close to 24 million individuals may be expected to have PCEHRs."

"The likelihood and level of security risk to PCEHR system data security will increase under an opt-out model due to the large number of individuals, as well as the richness of the volume of information. In particular, the registration of almost all Australians will increase its 'honeypot' value."

"There has already been criticism of the myGov website, with media arrticles pointing out flaws in its information security which hackers could have potentially leveraged to hijack myGov accounts, including accessing PCEHR records linked to those accounts."

"Some members of the public could be concerned about the extent to which greater uptake of the myGov system could lead to centralised government communications, data linkage between client agencies, and the like ... we suggest that the establishment of an alternative, stand-alone individual access portal for the PCEHR would eliminate these concerns, as well as addressing the compliance risks identified in relation to the Data Security and Access privacy principles."

Opt-out and Governance

CeHA has always had great concerns with Governance and the need to include consumers. Under the new My Health Record, the potential change from “opt in” to “opt out” would increase the importance of governance enormously because under “opt in” there would be some expectation that people would know what they were opting into and be able to make a judgement about their personal responsibility.

However under “opt out” the whole population would be nominally covered by a systemic mandate leading to changes in responsibility for the Department of Health or ACeH and hence changes in liability. This implies a significant requirement to change and strengthen governance.

Consumers will also be concerned to learn whether such an “opt-out” mandate might extend to service providers.

We are pleased that the proposed governance changes include consumer representation along with all other stakeholders and recommend that these changes be organised on a basis that enables joint cooperative collaboration at all levels.

OTHER MATTERS

Healthcare identifiers

The review of the Healthcare Identifiers Act and Service is now more than two years' old, and was conducted at a time when use of the HI service was minimal.

"*Consequently, some of the issues associated with the functionality that has been built, the policies and processes surrounding the HI service, and implementation processes are only now starting to emerge,*" the review says.

"*As new health systems and services begin to integrate with the HI service it is inevitable that issues will be identified that were not anticipated at the time of development.*"

According to Medicare's annual report[7] on Healthcare Identifiers, Individual (patient) Healthcare Identifiers were accessed around 52 million times in 2013-14. The service operator reported a further 82,270 IHIs were disclosed via its call centre and fax channels.

The National E-Health Transition Authority provided an interesting explanation in its own annual report. "*There were around 52 million unique searches of IHIs via electronic channels this year for use in clinical information systems and clinical documents to support ongoing jurisdictional data quality initiatives and to authenticate access to e-health products.*"

In other words, the look-up service was only used very infrequently by real users.

CeHA considers it timely to review the Act and Service again, in the light of the PCEHR system potentially being applied to the entire population, with such review conducted by an independent audit.

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[7] Review of HI Act and Service, June 2013
http://www.health.gov.au/internet/main/publishing.nsf/Content/91134273A157B7B0CA257C350014D786/$File/Healthcare-Identifiers-ACT-and-Service-Review-WEB.pdf

While every Australian has already been issued with an IHI, these identifiers were created by Medicare from its own databases - which were known to hold much duplicated or erroneous data.

Given the modest usage to date - almost entirely for test purposes - it is clear the HI system has not been stress-tested. There is great potential for patient harm if there are mistakes with names and record numbers.

MyGov accounts

CeHA also has deep reservations about the use of the Australian Government single sign-on portal, myGov, being a necessary prerequisite for personal access to their own records.

In combining the uniquely identifying IHI and myGov account, the Government has created a single storage source of personal information about every citizen, rather than the original federated design proposed in NEHTA's *Concept of Operations* (see figure 10).

There are consumer concerns that this database effectively creates a "virtual" Australia Card - a national identity scheme that has been roundly rejected by the populace on several occasions.

A myGov privacy impact assessment[8] conducted by HWL Ebsworth in early 2014 notes: *"Importantly, it will remain optional for individuals to use myGov or create a myGov account to access Australian Government services."*

"*Member services (Centrelink, Medicare and the Australian Tax Office) will retain existing face to face and telephone channels for individuals who do not wish to access services through their myGov account. Some have also retained online services which are accessible outside of myGov.*"

Yet no-one will be able to access their e-health record, including initially, to set access controls, without first registering for a myGov account.

Crucially, in an opt-out system, many people will have no idea that an online record has been created for them, and that healthcare providers (and potentially others) are accessing their medical information as they see fit.

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[8] Ebsworth PIA on myGov http://www.humanservices.gov.au/spw/corporate/publications-and-resources/resources/mygov-profile-privacy-impact-assessment.pdf

We note that the Department of Human Services agrees with the PIA's recommendation that it implement "*processes to monitor and manage privacy issues arising from myGov function creep*", but it is unclear whether the DHS has taken any action on this or any other recommendation.

Large swathes of the PIA have been redacted, raising suspicions that the assessment found some pretty serious problems.

Minter Ellison has also singled out the one-channel access to the PCEHR as a barrier to acceptance (see comments, above), and suggests a standalone individual access portal as a means of resolving these concerns.

CeHA recommends that a PIA be conducted specifically into the suitability of myGov as the sole channel for personal access to e-health records, rather than the original design proposals.

Former Health Minister Nicola Roxon undertook that the then-Government would not create a single repository for personal medical information. The myGov portal arrangements seem to overturn this undertaking, with all the attendant risks.

CONCLUSION

The Real Issue:- Why is eHealth so Hard ?

This question has often been raised. The answer has long been known - but continues to be avoided !

WE suggest that the key factor has been lack of governance appropriate to the task.

The nature of the required governance was clearly spelt out in the principal recommendation in the Health Online final report to Parliament in 2001.

This report and most others since have recommended the involvement of all key stakeholders in a collaborative Governance/Management structure from day one. This would bring their operating needs to immediate attention and could be promptly reconciled within a teamwork environment.

The allied aim would be to avoid a repeat of a silo mentality that so often arises when the various interest groups are kept apart rather than developing a dedicated teamwork spirit actively engaging within an integrated framework.

The Department of Health and NEHTA have been struggling for almost 11 years now, yet have produced few practical results for the cost to date.

A string of consultants' reports have found issues and concerns, and scant evidence of worthwhile implementations and outcomes despite more than $1 billion in spending.

The Royle and Deloitte consultations have confirmed this, and in their reports they recommend significant changes in governance.

We should not carry on for an extended period without speedily acting on their advice, which involves creating a teamwork structure involving all key stakeholders.

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Appendix - (CeHA) Consumers e-Health Alliance

INTRODUCTION

The Consumers e-Health Alliance (**CeHA**) is an unincorporated not for profit organisation. Its partners cover many leading chronic illnesses, disabilities and carer organisations along with individual members.

Convenor: Peter Brown

Steering Committee

Peter Brown (Cancer Voices Australia)
Russell McGowan (Health Consumer Council - ACT)
Anna Williamson (Leukaemia Foundation)
Eric Browne, Carer (formerly involved with Health*Connect* Program)
Dr Janet Wale (Cochrane Consumer Network)

CeHA is a collective of consumer oriented organisations and people who have displayed active positive interest in the e-Health program. Our activities are to highlight the need to engage with all affected health industry sectors within the Governance, Leadership and Management of the national electronic infrastructure system. We espouse the need for community wide:-

Communication | Co-operation | Collaboration | Coordination

Keep It Simple

CeHA seeks agreed standards at all levels and for all affected community sectors to be appropriately represented at the same table at the same time. CeHA provides the avenue for the tabling of ideas, concerns, needs, information on e-health in which development we have a common interest and which directly affects the individual lifestyles of every citizen including their individual health needs at all times.

CEHA ASSOCIATES

Alzheimer's Australia
Aged Care Association Australia - NSW
Arthritis Australia
Asthma Foundation
Australian Diabetes Council
Australian Lung Foundation
Cancer Council Australia
Cancer Voices Australia
Carers NSW
Carers WA
Cochrane Consumer Network
Health Consumers Alliance - SA
Health Consumer Council - ACT
Health Consumer Council - Q'LD
Health Consumer Council - WA
Health Consumers of Rural and Remote Australia
Kidney Health Australia
Kimberley Aboriginal Medical Services Council
Leukaemia Foundation of Australia
National Heart Foundation
National Stroke Foundation
Parkinson's Australia Inc.
PRA Mental Health Recovery
Private Mental Health Consumer Carer Network (Australia)
Tasmanians with Disabilities
The Country Women's Association of Australia