Australian Privacy Foundation

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APF submission to Inquiry into the provisions of the Personally Controlled Electronic Health Records Bill 2011 and a related bill.

The Australian Privacy Foundation (APF) is the country's leading privacy advocacy organisation. I write as Chair of the Health Sub Committee of the APF. I refer to the Community Affairs Legislation Committee Inquiry into the Personally Controlled Electronic Health Records Bill 2011 and the Personally Controlled Electronic Health Records (Consequential Amendments) Bill 2011.

Our submission is organised in two Sections. Section one is a summary of our submission; section two details this in full.

Yours sincerely

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Section 1

Executive Summary

The APF welcomes this opportunity to influence much needed eHealth Bills in Australia. Government focus on these endeavours is to be applauded. Examples of effective programs exist overseas and we are anxious to learn from them. An effective Australian eHealth system existed in many States and Territories prior to the commencement of work on the national PCEHR system. We are keen to see our eHealth system function at least as effectively as other useful International programs. Thus our feedback on the system enshrined in the Bills is summarised below.

1. The APF is concerned that reverse engineering of governance issues at the heart of the PCEHR system will adversely affect health professional and patient use of such.
2. The APF believe it is crucial that Non-Government funded citizen Organisations (NGOs) are offered permanent advisory roles on governance bodies that will probably be established post PCEHR system roll-out, as has been mooted during discussions with health authorities this year.
3. The APF maintains that the Bills require governance benchmarks so that citizens may verify PCEHR system performance, security and privacy functionality themselves, independently of Government agencies.
4. The APF is not comfortable as to the conflict of interest that Government employees must manage under the Bills should an individual citizen be concerned about unauthorised access to their IHI, PCEHR and associated data.
5. The APF asks that minimum terms, rights and responsibilities for individuals' and healthcare providers' participation in the context of the PCEHR system are legally specified in the Bills.
6. The APF is concerned that the proposed PCEHR standards mash-up will trigger a cascade of costs and barriers that health practitioners, island-Australian software manufacturers and the community will be forced to suffer, while individual patients will suffer adverse health errors due to the resultant loss of data confidentiality, integrity and availability.
7. The APF enquires whether the Australian Government, and so all tax payers, will bear the industry and health practice costs of failed PCEHR system standards implementation.
8. The APF requests information about what else, other than standards, will be compromised in order to meet the PCEHR system deadline of July 2012.
9. The APF believes it is fundamentally important, in keeping with patients' basic rights, that the absolution of Government jurisdictions and their agents is removed from the Bills. Misuse of the data must be subject to consequences, especially given many unwilling patient participants at Lead Sites. The right to litigation when unfairly impacted by another's action occurs in the general community and is supported by the recent ALRC review of Privacy laws**.** The Bills need to reflect community standards of accountability.
10. The APF asks to be informed of the total expenditure figure Government has invested thus far and will invest in the PCEHR system to July 2012.
11. The APF is concerned by the influence of the failed IHI implementation and the retention of local systems combined with the PCEHR overlay on quality patient care outcomes and clinician training and workload. Neither Bill specifies benchmarks or independent bodies to measure these factors as outcomes. We ask that the Bill be amended to specify such benchmarks and to ensure the information is publicly available rather than confidential or outside the scope of Freedom of Information requests to NEHTA, as often occurs at present.
12. The APF is concerned that the Bills do not embody informed consent arrangements and that citizens are not being advised by federal authorities about the breadth and depth of data Australian Governments hold, use, disseminate and data mine about individuals without consent.

13. The PCEHR system embedded in the Bills is a document viewing service and not a patient care system at all. The APF questions marketing efforts to convince patients and practitioners otherwise[2-4]. The APF therefore asks how the system, which cannot uniquely identify individuals and simply permits document transmission and viewing, will be used for patient care benefit at all.

14. The Bills still do not define the term "health provider". The APF wonder precisely who will and will not be able to use the PCEHR system; this includes summaries of patient care information via the Internet for those unable to directly connect to individual patient electronic health records.

15. The APF has been alarmed to note recent press reports suggesting the PCEHR system ought to be "opt out" rather than "opt-in". The reports, which quote many prominent Australians, suggest the proposed PCEHR system architecture enabled by the Bills, are not generally understood. If the PCEHR system is "opt out" then all health practitioners will be forced to register for the PCEHR system as health providers and citizens alongside individuals from the broader community. The current PCEHR system architecture cannot function as an "opt-out" system.

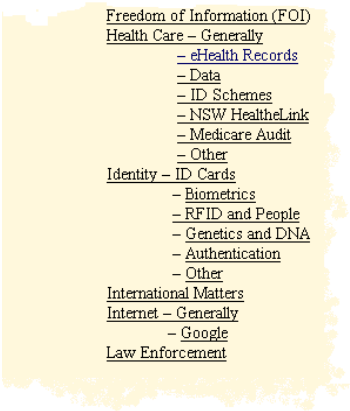
16. Finally, neither Bill details the eHealth services that will actually be achieved by July 2012. It is better to get this Government initiative right than to meet an arbitrary deadline. Everyone is a health consumer so getting a national eHealth system wrong would be very costly in terms of public perception of the Government and set our national eHealth agenda back several years. The Bills should refer to actual deliverables and benchmarks over and above simply enabling a PCEHR system experiment with clinicians and the broader community in living laboratories.

Section 2

Introduction

International experience has demonstrated that a systematic and transparent approach must be taken to privacy compliance in order to achieve a trustworthy PCEHR system upon which patients and health workers can rely [(1)]. The APF has made many attempts to communicate with the national E Health Transition Authority (NEHTA) and the Department of Health and Ageing (DoHA) in systematic and transparent ways over several years, as the partial screenshot from our website, below, illustrates. Despite claims to the contrary, effective consultation (i.e. meaningful two way communication) with consumer advocacy NGOs began to occur and then ceased in 2011 - that is for a period of less than a year, while Government plans to deliver a national PCEHR system have been in place for more than five years. In this context, the "the Personally Controlled Electronic Health Records Bill 2011" and "the Personally Controlled Electronic Health Records (Consequential Amendments) Bill 2011" are disappointing.

Selected APF Papers Sorted by Policy Topic



http://www.privacy.org.au/Papers/indexPolicies.html
Screenshot 1: Section of more than 2 e-pages of APF letters, submissions and papers sorted by "Health Care"

I have attached copies of pertinent APF policy documents and previous submissions regarding the PCEHR Draft Legislation, the PCEHR Concept of Operations and a letter to the Minister of Health, NEHTA and DOHA to this submission to avoid repeating APF feedback previously submitted to health authorities on the key issues [(2-5)]. The three submissions were made to the Department of Health and Ageing in 2011 and the letters to the Minister and other senior health authorities were also sent during 2011. All of these and further related documents are publicly available on the APF web site. Despite their exclusion from the body of this submission, matters raised therein are of vital importance. We request consideration of these papers as supplements to this submission.

This submission focuses on five key themes. They are poor governance, "Island Australia" standards, Government agent's immunity from responsibility, the quality of patient care and growing Government stewardship of centralized information about its citizens. Each topic is covered in a section listed below.

Governance

Neither of the Personally Controlled Electronic Health Records Bill 2011 and the Personally Controlled Electronic Health Records (Consequential Amendments) Bill 2011 (the Bills) outlines the governance framework which has informed their development let alone the PCEHR system development itself. Motherhood statements and general governance principles are documented without any form of operationalisation. The matter of governance, a concept at the heart of successful project planning, has been largely overlooked until late 2011. Governance concerns are at the core of initial project planning processes rather than a concept that can be retrofitted once a system has been designed.

1. The APF is concerned that reverse engineering of governance issues at the heart of the PCEHR system will adversely affect health professional and patient use of such.

The Bills enable the minister to make PCEHR rules, requires the Information Commissioner and the PCEHR System Operator to report annually and provides for a review of the first two years of the operation. However there is no indication in the extensive Bills of system benchmarks or ways governance success or failure of the system may be judged and no scientifically valid evidence is referenced either. For instance, all Australian were issued with an Individual Health Identifier (IHI) number, which links to personal and health information, in July 2010 and these have been downloaded in batches by various health professionals for local use. The local use includes saving the records to practice information systems and circulating them to colleagues, many of whom in turn save them to their own computerised information systems, mobile phones and computer tablets. The majority of patients, let alone health authorities and other health professionals, are unable to measure or control all locations where information about an individual is actually stored at present. Thus, effectiveness of the PCEHR system cannot be measured by IHI download rates or use in health settings because there are no valid boundaries for such enquiry.

Discussions with health authorities this year suggest that advisory bodies will be formed to evaluate the effectiveness of the PCEHR system after July 2012. We believe it is vital to include Non-Government funded citizen Organisation (NGO) representatives on these advisory bodies to avoid perceptions of a conflict of interest. Such appointments would also demonstrate Government confidence in the PCEHR system.

2. The APF believes that it is crucial that Non-Government funded citizen Organisations (NGOs) are offered permanent advisory roles on governance bodies that will probably be established post PCEHR system roll-out.

Governance is a key system benchmark yet thus far patients have been forced to rely upon press releases or Government-linked websites for all information about the privacy and security of the health information about themselves. Conversely Government health authorities are able to store, use, uncontrollably disseminate and access such data. Current IHI evidence is unreliable for governance research and assessment purposes, and no other performance benchmarks have been publicly revealed. Frankly, the IHI Bills and the current Bills before the Senate suggest that citizen expectations about their power to understand where health and personal information about them is stored no longer exists in Australia.

3. The APF maintains that the Bills require governance benchmarks so that citizens may verify PCEHR system performance, security and privacy functionality themselves, independently of Government agencies.

We are alarmed to understand that Government agencies, as specified in the Bills, will steward all information stored in one's PCEHR, one's IHI and all data from the Centrelink and Medicare megamerger. There is a history of poor governance in the context of managing Australian health data [(3)]. For example, in late 2011 the Federal Court found that Medicare had illegally merged patient health and personal data. Medicare also faced (and probably still does) a plethora of accusations about the way their investigations are handled [(6)]. The weakened frameworks will enable linked data storage of two or more discrete information systems storing personal and health information to be co-located in the same data base (see above). Yet the Government is working to diminish protections embedded in Professional Services Review legislation so Federal Court challenges to database mergers of indexed health information may not continue. [(6)] Such diminishment erodes citizen rights to privacy and security as a fundamental human right.

The heavily publicised audit proposals embedded in the Bills take no account of human factors or of the fact that current audit systems, upon which the proposed Bills rely, are dysfunctional. One simply needs to look at the evidence to see that health authorities either amend legislative frameworks to authorise presently illegal data hosting requirements (see above) or ignore these concerns completely, as per the following example. An attached submission outlines instances of where patient information stored in pharmacies dismally failed recent Australian National Audit Office (ANAO) audits yet DoHA failed to act because it had received no direct complaint made by an individual patient[(2-4)]. Individuals can only ever discover such a breach under the proposed PCEHR system Bills if the Government agency employee with whom they make such enquiries judges that it is appropriate to pass on the information. Anecdotally, we understand that health authorities have acted to ensure that news of such breaches is not publicly available[(20)]. We ask whether individuals enquiring about their own records will be subject to similar censorship. The Bills ensure that Government employees, as

public custodian of the data, are inextricably conflicted in the context of breach enquiries and Government plans to advance the PCEHR system.

Further, in APF experience, information breaches are often discovered months after occurrence and can foster litigation. The community expect DoHA and other Government agencies to control breaches, such as in the instance of the pharmacy example above, on their behalf rather than await individual complaints before taking action. Suggestions, as with changes to the Professional Services Review discussed above, magnify our concern as to the community's right of action

4. The APF is not comfortable as to the conflict of interest that Government employees must manage under the Bills should an individual citizen be concerned about unauthorised access to their IHI, PCEHR and associated data.

The Bills do not explain minimum terms, rights or responsibilities for individuals' and healthcare providers' participation in the PCEHR system. There are no complaints mechanisms embedded in the Bills. Individuals will not be able to directly access audit information about their PCEHR system records except via the Government and its agencies[6]. The APF is distressed to note that when Government agencies do not comply with robust legal governance frameworks it is the protection such frameworks offer to people that are weakened as a result, to the cost of their individual human rights.

5. The APF asks that minimum terms, rights and responsibilities for individuals' and healthcare providers' participation in the context of the PCEHR system are specified in the Bills.

Standards

International standards are a non-negotiable foundation of the complex PCEHR system. Standards define record formats (that is the range of fields to be populated by end-users), vocabulary and terminology, syntax, the seven machine layers for a health message to move between locations, hardware requirements and all the business processes at every point in the interoperability chain. Despite ongoing concerns expressed by the Medical Software Industry Association (MSIA) and the Australasian College of Health Informatics(ACHI) as well as consumer advocacy groups such as the APF as to the requirement for a single international standard to underpin the establishment of the national PCEHR system, NEHTA's Tiger Teams and other agencies such as the International Health Terminology Standards Development Organisation (IHTSIDO) have attempted to retrofit these to the PCEHR system architecture[7-9]. The Tiger Teams were initiated as a way to devise useful national eHealth standards[10]. As of November 2011, the Tiger Teams had not met, yet ostensibly managed to harmonise several very complex standards for an Australian EHR by month's end. This unseemly rush undermines community trust in the local and International standards that were allegedly harmonised without a governance framework. We wonder what other aspects of the project will have to be compromised like this to meet the 1 July 2012 deadline. The rushed mash-up of several different national and international standards ostensibly underpin the system, which could lead to medico legal liabilities and dangerous outcomes for patients.

The standards mash-up is potentially costly for clinicians in other ways too. Anecdotal evidence suggests not all health organisations, especially private practitioners and specialists, will opt-in to the system. Patient care will be based on this "mish-mash" of standards and computer operating systems that the evidence shows have not ever been able to exchange data effectively[1]. Indeed, we understand this issue remains vexed in the current PCEHR lead site settings. There are currently nine lead sites, or health care organisations, trialling the PCEHR system across Australia. The mash-up will diminish Data Confidentiality, Integrity and Availability (data-CIA) so that records stored in the PCEHR system will provide an unreliable basis for patient care, as occurred with the doomed Health Care Summary project in the UK [1]. Unlike the definition of data integrity expressed in the Security and Access Framework document, and presumably a foundation of the PCEHR system, data integrity actually incorporates the accuracy and completeness of information and processing methods and is not simply a measure of tamper-proof communication systems[11-12]. The Bills show no evidence of a common understanding of what is required to underpin a PCEHR system that patients and clinicians can trust.

This diversion from a single International standard will result in an "island Australia" PCEHR system. Australian industry, patients and health professionals will be confronted by a series of cascading costs and barriers as the direct result of the bridges planned between current systems and those required to use the PCEHR system [9]. Australian business will be unable to function competitively in an international setting whereby one standard applies locally and another applies overseas. Patients who choose to do so will not be able to link to their

supposed electronic health record (EHR) from other countries. Current multinational research and business entities working on ways to exchange health data between countries will be hampered. Suppliers of hardware and software are likely to face an inefficient and incompatible system that adversely impacts on return on investment (ROI) and, in terms of the domestic software industry, may even result in business failure if companies work to develop applications for Australian eHealth.

Proposed PCEHR system standards are likely to lead to increased costs for medical practitioners looking to bridge current practice software, which complies with an earlier data exchange standard, to new mash-up PCEHR system standards. The issue is magnified when, at a later stage, clinicians will have to upgrade systems once more to work to a single, effective International standard for global health information exchange. Even practitioners that do not opt into the PCEHR system in the first instance will be caught up in this concern.

Also, a patient may have registered for a PCEHR on 1 July 2012, but the health professional they consult may not yet be capable of entering data on to that patient's electronic record. The Bills do not contain any provision to address this very real and likely dilemma but the community will need to manage the issue through Government agencies post July 2012. This unwieldy process will be foisted on the Australian community regardless of the very real concerns outlined herein.

The Bills do not discuss standards for the exchange of information on mobile information and communication technology (ICT) platforms or cloud computing protocols. Anecdotal and research evidence indicates the application of these tools is pervasive in patient care settings for two reasons. Firstly, in public hospital settings, clinicians often avoid reliance on shared, computing equipment with applications that do not communicate with each other on the single machine let alone other computers in the same room or building[13]. Secondly, clinicians require evidence at the point of patient care. However the application of these tools place clinicians and the health organisations in a grey medico-legal situation that only litigation will clarify. This is an untenable situation that has been forced on clinicians and patients due to ongoing disregard of such useful tools in national eHealth Bills, both proposed and in existence.

6. The APF is concerned that the proposed PCEHR standards mash-up will trigger a cascade of costs and barriers that health practitioners, island-Australian software manufacturers and the community will be forced to suffer, while individual patients will suffer adverse health errors due to the resultant loss of data-CIA.
7. The APF asks whether the Australian Government, and so all tax payers, will bear the industry and health practice costs of failed PCEHR system standards implementation.
8. The APF requests information about what else, other than standards, will be compromised in order to meet the PCEHR system implementation deadline of July 2012.

Immunity from responsibility

The Bills ensure the Government and associated agencies are devoid of any responsibility for adverse health errors, stolen or misused data from centralised databases and practitioner ICT systems. As indicated in an earlier submission to DoHA, the move allows Government departments and contractors to continue conducting their living laboratory experiment, as represented by the PCEHR system Bills, without concomitant responsibility for their actions[2]. Based on feedback received via the community and mentioned in earlier submissions to NEHTA and DoHA, the pre PCEHR system implementation experiment depends on findings from research involving many unwilling patient-participants at the Lead Sites. The APF questions the approach of those who devised the Bills in a way that the National Health and Medical Research Council (NHMRC) has deemed as unethical[14].

Recently the former minister, the Honourable Nicola Roxon, attempted to address these concerns. However her statement to the press indicated that the Government has not changed its position, but has merely talked around the edges of a mismatch between community standards of responsibility and those held by the architects of the PCEHR system[15]. Yet we know that 85% of Australians are unhappy about carelessness with their data privacy and security; around half of these are prepared to litigate in instances of data breach[16]. A key finding from the recent Australian Law Reform Commission (ALRC) review of the national privacy regime highlighted the need to legislate a private cause of action where an individual has suffered a serious invasion of privacy[19]. Regardless, the Bills ensure the Government and employees of the Government cannot be held to account for their PCEHR and IHI system actions, while contractors may well not be liable either. If

Government and associated agencies and contractors require different provision arrangements from others then these need to be specifically articulated in the Bills. The blanket exemption for the Government and their agents totally disregards community standards of accountability.

9. The APF believes it is fundamentally important, in keeping with patients 'basic rights, that the absolution of jurisdictions and their agents are removed from the Bills. Misuse of the data must be subject to consequences, especially given many unwilling patient participants at Lead Sites. The right to litigation when unfairly impacted by another's action occurs with the general community and is supported by the recent ALRC review of Privacy laws[19]. The Bills need to reflect community standards of accountability.

Quality of patient care

The APF is concerned about the quality of patient care outcomes if the PCEHR system is founded on the IHI database. A recent security paper auspiced by NEHTA states that due to lack of confidence in the capacity of the IHI to uniquely identify patients, they will also be allocated parallel, service provider identifiers to ensure clinicians work on the right patient with the right information at the right place, at the right time [17]. Accordingly, the Government has authorised a system for mandatorily and uniquely numbering all citizens from birth to grave for one purpose, whereas the architects of the PCEHR propose to use the IHI for a contradictory purpose. The contrary purpose will magnify existing confusion in clinical settings where at least two identifiers will apply to every patient and may actually increase rates of adverse health error.

The IHI concern is exacerbated by new, machine-based, standard clinical terminologies Australian health workers will have to learn in order to use the PCEHR system at all. Along with medical and other health training requirements, Australian health workers must now learn a new discipline – the PCEHR system clinical terminology. Given ongoing reliance on local practice systems, reliable individual health records will depend upon the effective application of double language. Also, health workers will be forced to double-handle all patient care records in the context of unhelpful budgetary and productivity constraints[13]. One process will be used to care for patients and the other will be used to satisfy the machine requirements of PCEHR systems. The bi-lingual and double-handling nature of the proposed system in addition to the imposition of machine-based clinical terminology on time-poor health workers seems likely to foster data fragmentation and data-CIA errors, key concerns which the PCEHR system was ostensibly designed to address.

The adverse outcomes are particularly likely in the context of overwhelming eHealth workforce shortages across the sector. The shortage has fostered development of the Australian Health Workforce Institute (AHWI). Aside from research into the subject, the APF is not aware of any training endeavours actually initiated by the AHWI in the context of the shortage. While acknowledging the importance of research and development work, we would argue the reality of the PCEHR system and the lack of suitably qualified workforce are contraindicative issues that take precedence over academic research endeavours at present. Real patients and real clinicians will be relying on the PCEHR in real life from July 2012. Our analysis of Government expenditure to support the Australian health workforce shows this has been minimal and ineffective thus far. Anecdotally for instance, we understand that Australian medical students do not know what the PCEHR system is yet let alone clinical terminologies and neither are taught in any clinician training syllabus. This lack of knowledge and the workforce vacuum are bound to adversely impact on eHealth quality of care outcomes for many years to come.

An analysis of electronic practice has recently commenced based research networks in NSW. The analysis suggests there is evidence to support ideas about increased rates of patient care error when clinicians depend upon eHealth systems without valid and reliable data quality assurance mechanisms "and suffer an interoperability problem where information aggregated from diverse systems may be misinterpreted because of different meanings and contexts for care"[18, 21]. The report suggests "routinely collected electronic health care data [is] aggregated into large databases [that] are increasingly being mined, linked and used for audit, continuous quality improvement in clinical care, health service planning, epidemiological study and evaluation research"[18]. That is, the databases are not simply being used to improve patient care outcomes but also provide a fertile source of information for health administration, planning and research. The PCEHR overlay seems likely to amplify concerns linking error to data quality concerns. The mixture of uses may hamper the reliability of care information stored on the systems. The findings of researchers' investigations seem to suggest a plausible relationship between increased reliance of clinicians on some eHealth systems for patient care and adverse health effects.

After spending untold amounts of tax payer funds, Australian health care is likely to prove as dysfunctional post PCEHR system implementation and with as many "rail gauge" issues as occurred previously.

10. The APF asks to be informed of the total expenditure figure Government has invested thus far and will invest in the PCEHR system to July 2012.

11. The APF is concerned by the influence of the failed IHI implementation and the retention of local systems combined with the PCEHR overlay on quality patient care outcomes and clinician training and workload. Neither Bill specifies benchmarks or independent bodies to measure these factors as outcomes. We ask that the Bill be amended to specify such benchmarks and to ensure the information is publicly available rather than confidential or outside the scope of Freedom of Information requests to NEHTA, as often occurs at present.

Government stewardship of centralized information

The APF has noticed a trend towards increased Government stewardship of centrally managed and often co-located identified or identifiable information about all Australian citizens. Our concern about the mega-merger of Medicare and Centrelink data is exacerbated when one considers PCEHR records that are linked to the Medical Benefits Scheme, the Pharmaceutical Benefits Scheme, organ donor and childhood immunisation register. As our submission suggests, Government spokespersons have agitated for weaker privacy legal frameworks to enable linked data storage of two or more discrete information systems storing personal and health information to be co-located in the same data base too (see Governance, above).The APF therefore enquires about the existence of informed consent arrangements in the Bills to underpin such mega-mergers of information and about mechanisms to publicise the details of the centralisation to Australian citizens.

12. The APF is concerned that the Bills do not embody informed consent arrangements and that citizens are not being advised by federal authorities about the breadth and depth of data Australian Governments hold, use, disseminate and data mine about individuals without consent.

Miscellaneous and conclusion

13. The PCEHR system embedded in the Bills is a document viewing service and not a patient care system at all. The APF questions marketing efforts to convince patients and practitioners otherwise[2-4]. The APF therefore asks how the system, which cannot uniquely identify individuals and simply permits document transmission and viewing, will be used for patient care benefit at all.

14. The Bills still do not define the term "health provider". The APF wonder precisely who will and will not be able to use the PCEHR system; this includes summaries of patient care information via the Internet for those unable to directly connect to individual patient electronic health records.

15. The APF has been alarmed to note recent press reports suggesting the PCEHR system ought to be "opt out" rather than "opt-in". The reports, which quote many prominent Australians, suggest the proposed PCEHR system architecture enabled by the Bills, are not generally understood. If the PCEHR system is "opt out" then all health practitioners will be forced to register for the PCEHR system as health professionals and citizens alongside individuals from the broader community. The current PCEHR system architecture cannot function as an "opt-out" system.

16. Finally, neither Bill details the eHealth services that will actually be achieved by July 2012. It is better to get this Government initiative right than to meet an arbitrary deadline. Everyone is a health consumer so getting a national eHealth system wrong would be very costly in terms of public perception of the Government and set our national eHealth agenda back several years. The Bills should refer to actual deliverables and benchmarks over and above simply enabling a PCEHR system experiment with clinicians and the broader community in living laboratories.

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