



**Response to Request for Review
of the
Personally Controlled Electronic Health Record (PCEHR)**

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Australasian College of Health Informatics

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Executive Summary

***"Automating a bad practice only makes that bad practice more efficient"*¹**

The Australasian College of Health Informatics (ACHI) welcomes this opportunity to review the "Personally Controlled Electronic Health Record (PCEHR)" as requested by the Department of Health in November 2013.

The College is the professional body for Health Informatics in the Asia-Pacific Region. The credentialed Fellows and Members of the College are national and international experts, thought leaders and trusted advisers in Health Informatics. ACHI sets standards for education and professional practice in Health Informatics, supports initiatives, facilitates collaboration and mentors the community. The Fellows and Members of the College are widely involved in e-Health research, standards development, system design and implementation work in Australia, the region and globally.

ACHI supports the Australian government's national health reform agenda as informed by the National Health and Hospitals Reform Commission, the Primary Health Care Reform Report and the National Preventative Health Strategy Roadmap. We welcome an agenda that aims to create an improved healthcare system that is safe, of high quality and which is transparent, accountable, affordable and sustainable. We also appreciate the Commonwealth's efforts to establish eHealth infrastructure as well as build and operate an electronic health records system.

The College agrees that e-Health is an important enabler to the way healthcare will be delivered in the future. The College is supportive of electronic health records (EHRs) that primarily support the management of health care information in accordance with the WHO charter.^{2 3 4} The effective management of health care information during the clinical decision making processes provides the data and information necessary for the continuous measurement of health care, its quality and outcomes.⁵

Therefore, the College welcomes the Department's review of the "Personally Controlled Electronic Health Record (PCEHR)" as part of the refresh of the eHealth strategy. The Fellows and Members of the College have reviewed the operation of the PCEHR and have identified issues that may constitute reasons for a slow take up, recommendations on how to improve adoption/usage and improvements that may help realise the benefits from the substantial national investment.

In summary, the College believes that the current implementation of the PCEHR will not get wider adoption and usage until a number of shortcomings and failings of the current PCEHR implementation are rectified and has formulated **22 actionable recommendations** for the Department's consideration:

Recommendation 1: That the Department revisit the College's Response to Request for Comment on the Draft PCEHR Concept of Operations.

¹ Inspired by www.fierceemr.com/story/ehr-workarounds-poor-documentation-cause-deaths-memphis-va/2013-10-29

² Leao BF. Terms of Reference for Designing the Requirements of the Health Information System of the Maputo Central Hospital and Preparation of the Tender Specifications. Geneva: World Health Organization. 2007

³ Kanter AS, Negin J, Olayo B, Bukachi F, Johnson E, Sachs SE. Millennium Global Village-Net: bringing together Millennium Villages throughout sub-Saharan Africa. *Int J Med Inform.* 2009;78(12):802-7

⁴ Tierney WM., Kanter AS., Fraser HSF., C. B. A Toolkit For eHealth Partnerships in Low-Income Nations. *Health Affairs.* 2010;29(2):268-73.

⁵ Wolfe BA, Mamlin BW, Biondich PG, Fraser HS, Jazayeri D, Allen C, et al. The OpenMRS system: collaborating toward an open source EMR for developing countries. *AMIA Annu Symp Proc.* 2006:1146.

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Recommendation 2: *That the Department initiate a broad-scoped and open PCEHR Review.*

Recommendation 3: *That the Department critically appraise the consultation input reported by NEHTA and note that some PCEHR acceptance issues may have been created by biased feedback.*

Recommendation 4: *That the Department clarify the intent, objectives and purpose of the PCEHR, determined by the goals and objectives to be achieved.*

Recommendation 5: *That the Department initiate a redesign of the PCEHR based on effective clinical consultation and a business case that includes time spent on e-health activities.*

Recommendation 6: *That the Department amend the PCEHR Act 2012 and/or the relevant Regulations and Rules to ensure that any non-care-related use of the PCEHR data is in line with existing legislation and legal precedents.*

Recommendation 7: *That the Department amend the PCEHR Act 2012 and/or the relevant Regulations and Rules to eliminate any unreasonable legal sanctions on bona-fide users.*

Recommendation 8: *That the Department amend the PCEHR Act 2012 and/or the relevant Regulations and Rules to include the liability of the Crown for PCEHR errors in line with its liability for other public services it has responsibility for.*

Recommendation 9: *That the Department clarify the issue of PCEHR "patient control" while balancing the expectations of clinicians with the expectations of consumers. This will require extensive consultation and consensus-building with both groups of stakeholders.*

Recommendation 10: *That the Department note the opportunity for improved patient care outcomes as well as efficiency and productivity gains that may arise as a result of the integration of appropriate health informatics platforms in the aged care and dementia care sectors.*

Recommendation 11: *That the Department consider causing a dialogue with designers and builders of health informatics platforms for aged and dementia care facilities to be established in order to evaluate the role and benefits of the integration of aged care health information into the PCEHR*

Recommendation 12: *That the Department lead the development of a National Health Standards Roadmap with input from health informatics, clinical and industry experts*

Recommendation 13: *That the Department review its contractual arrangements with NEHTA and Standards Australia to ensure that its support for the standards process is fully congruent with Standards Australia's consensus-based standards development guidelines.*

Recommendation 14: *That the Department revise the PCEHR's clinician-faced functionality to ensure it can reliably and accurately automatically capture and provide the information and is fully integrated with clinician workflows*

Recommendation 15: *That the Department direct the PCEHR implementers to re-engineer its clinician-faced functionality and useability*

Recommendation 16: *That the Department cause the creation of simple "plain-English" education materials for clinicians*

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Recommendation 17: *That the Department cause the creation of a template curriculum and/or series of plans for educators*

Recommendation 18: *That the Department effect the inclusion of PCEHR education in medical education frameworks including AMC accreditation*

Recommendation 19: *That the Department publish a simple outline of the entities, meta data and rules that govern the privacy and security of the personal information within the PCEHR*

Recommendation 20: *That the Department improve the privacy controls and regulations for patient health data in the PCEHR*

Recommendation 21: *That the Department improve the remedies available to patients/consumers privacy controls and regulations for patient health data in the PCEHR*

Recommendation 22: *That the Department publish a simple outline of the entities, rules and processes that govern the privacy and security of the personal information within the PCEHR*

The Australasian College of Health Informatics looks forward to further working with DoH on the improvement of the PCEHR e-health systems that will enable the common goal of better healthcare for all Australians.

1: Experience on the Level of Consultation with Key Stakeholders during PCEHR Development

For any system that relies heavily on acceptance and usage by both professionals and the public, extensive consultation is required to ensure the system meets the needs and expectations of stakeholders for the system to have a reasonable chance of achieving successful uptake and utilisation.

The College believes that the consultation approach and processes employed during the PCEHR development were not always effective and in some cases provided poor guidance to the PCEHR developers.

While the retrospective "filtering" of lesser-quality consultation input is non-trivial, the College believes there are a few remedies that can still be effectively undertaken:

- a. The College provided extensive written input to the Request for Comment on the Draft PCEHR Concept of Operations Concept of Operations ("ConOps") in the PCEHR public comment phase with 46 detailed and actionable recommendations.⁶ The College believes that the implementation of these recommendations would have resulted in better acceptance and so increased uptake of the PCEHR by both clinicians and consumers.

Recommendation 1: That the Department revisit the College's Response to Request for Comment on the Draft PCEHR Concept of Operations

- b. The College believes that the scope and audience of this PCEHR Review is too limited. The College is concerned that the lack of a broad-scoped open PCEHR Review may result in a real or perceived lack of legitimacy of the outcomes of this Review.

Recommendation 2: That the Department initiate a broad-scoped and open PCEHR Review

- c. The College notes the widespread perception that the PCEHR consultations were "stage managed" by NEHTA. Many stakeholders believe that the initial feedback from NEHTA-linked GPs overrode the input from other clinicians.
- d. Some stakeholders have reported to the College that they felt they were not genuinely consulted, but felt they were "told what to think". In some cases, they observed that NEHTA scribes at consultation meetings failed to record significant feedback.

Recommendation 3: That the Department critically appraise the consultation input reported by NEHTA and note that some PCEHR acceptance issues may have been created by biased feedback

⁶ Response to Request for Comment on the Draft PCEHR Concept of Operations, Australasian College of Health Informatics (ACHI), June 2011 (V1.2) www.ACHI.org.au/docs/ACHI_Response-PCEHR_ConOps_V1.2.pdf

2: Use of the PCEHR by Health Care Professions in Clinical Settings

Nearly 18 months since the commence of the PCEHR operations, its regular use by clinicians is still minimal. This is despite payments to GPs through the Practice Incentives Program ("PIP")⁷ which are linked to participation.

The original goals⁸ of the Personally controlled Electronic Health Record are laudable

- To help overcome fragmentation of health information
- To improve the availability and quality of health information
- To reduce the occurrence of adverse medical events and the duplication of treatment
- To improve the coordination and quality of healthcare provided to consumers by different healthcare providers

However, the overwhelming view by clinicians is that the current implementation has left much to be desired. One of the identified root causes of the shortcomings and failings of the PCEHR is a lack of clarity and/or agreement of its overall purpose.

- a. The intent, objectives and purpose of the PCEHR, determined by the goals and objectives to be achieved need to be clearly defined, articulated and operationalised. The current implementation neatly glances its many customers' needs without making much of a difference to any of them. This combined with a deficiency in good governance including a culture which is the contrary of openness and transparency are some of the main issues.

Recommendation 4: *That the Department clarify the intent, objectives and purpose of the PCEHR, determined by the goals and objectives to be achieved*

- b. The PCEHR system needs to reflect actual clinician behaviour rather than system designer's interpretation of clinical work practices.
- c. The PCEHR has not been appropriately designed to integrate with the process of care in clinical settings, thus adding to rather than supporting clinician workload. Many clinicians are small business owners or work for small businesses, which are sensitive to any increase in workload without operational benefits and/or financial compensation.

Recommendation 5: *That the Department initiate a redesign of the PCEHR based on effective clinical consultation and a business case that includes time spent on e-health activities*

- d. There is increasing concern amongst the clinician community (in particular in General Practice) about non-clinical use of the PCEHR^{9 10}, specifically for:
 - Law enforcement purposes
 - Health provider indemnity insurance cover purposes
 - Research
 - Public health purposes
 - Other purposes authorised by law

⁷ For more details, see www.medicareaustralia.gov.au/provider/incentives/pip/

⁸ PCEHR Act 2012

⁹ <http://doctorsbag.wordpress.com/2013/09/23/the-pcehr-movingforward/>

¹⁰ <http://doctorsbag.wordpress.com/2013/08/05/pcehr-quiz/>

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GPs are concerned about these non-clinical purposes that are not directly related to the care they provide to their patients. Current practice is that patients and clinicians have to give informed consent before their health information can be used for research or other purposes.⁹

This is another factor that has undermined the acceptance of the PCEHR in particular by GPs.

Recommendation 6: *That the Department amend the PCEHR Act 2012 and/or the relevant Regulations and Rules to ensure that any non-care-related use of the PCEHR data is in line with existing legislation and legal precedents*

- e. The penalties attached to misuse of PCEHR data are perceived by some clinicians as too harsh and unrealistic. A system of training and warnings needs to be in place before any penalty is applied to a bona-fide user of the PCEHR

Recommendation 7: *That the Department amend the PCEHR Act 2012 and/or the relevant Regulations and Rules to eliminate any unreasonable legal sanctions on bona-fide users*

- f. The current PCEHR Act 2012 and/or the relevant regulations imply that the Crown is exempt from liability for any PCEHR system errors. This asymmetry to the legal sanctions prescribed for users of the PCEHR is of substantial concern to clinicians.

Recommendation 8: *That the Department amend the PCEHR Act 2012 and/or the relevant Regulations and Rules to include the liability of the Crown for PCEHR errors in line with its liability for other public services it has responsibility for*

- g. The concept of "patient control" and "consumer control" concerns clinicians with respect to any source information that can be trusted. The trust of clinicians is vital for the success of any Health IT system¹¹ as information that is either inaccurate or incomplete creates a substantial medico-legal risk to the clinician, his employer and his medical insurer.
- h. The systemic issue is data quality. Clinician trust is the result of consistent quality and reliability of the data provided.
- i. The media has repeatedly reported PCEHR data quality issues¹² (The College has first-hand reports of PCEHR data errors from its Fellows & Members)
- j. A health IT system that is not trusted will either not be used or its information ignored, leading to costly and potentially harmful retesting of patients.¹³ As a result, one of the main projected benefits of the PCEHR will not be realised.
- k. The issue of "patient control" and "consumer control" is in flux, although recently published research confirms that the points f-i above reflect the views of a significant number if not the majority of clinicians in Australia. However, the College has observed what may be a genuine shift in community expectations on this, the rising concern about perceived information asymmetry between patients and clinicians as well as an expectation of greater clinician accountability by consumers. This may currently be more evident in the UK and US, but Australia may not be too far behind those trends.

¹¹ www.healthcareitnews.com/news/emergency-departments-feeling-best-breed-remorse & www.sydney.edu.au/engineering/it/~hitru/index.php?option=com_content&task=view&id=120&Itemid=116 & <http://cci.drexel.edu/faculty/ssilverstein/patient%20safety%20and%20health%20it%20prepub.pdf>

¹² www.pulseitmagazine.com.au/index.php?option=com_content&view=article&id=1565:pcehr-exposes-more-examples-of-pbs-errors

¹³ www.sciencedaily.com/releases/2013/11/131104162712.htm

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Recommendation 9: *That the Department clarify the issue of PCEHR "patient control" while balancing the expectations of clinicians with the expectations of consumers. This will require extensive consultation and consensus-building with both groups of stakeholders.*

- e. The College believes that electronic health records (EHRs) such as the PCEHR should include health informatics data gathered in aged and dementia care settings, as this level of health informatics data is currently not being appropriately integrated into the PCEHR.
- f. Past experience suggests health informatics and eHealth systems will continue to play an extremely important role as a source of accurate and detailed information for inclusion in the PCEHR, especially in the area of aged and dementia care, a rapidly growing and in some respects relatively neglected portion the health sector.

Recommendation 10: *That the Department note the opportunity for improved patient care outcomes as well as efficiency and productivity gains that may arise as a result of the integration of appropriate health informatics platforms in the aged care and dementia care sectors*

- g. The College has received reports of the unwillingness, in some cases, of specialist PCEHR solutions providers to integrate important instrumented aged care patient / resident data into Electronic Health Records. The ethic of maximum quality and accessibility of health records should not be eclipsed by individual PCEHR suppliers' perceived commercial interests.

Recommendation 11: *That the Department consider causing a dialogue with designers and builders of health informatics platforms for aged and dementia care facilities to be established in order to evaluate the role and benefits of the integration of aged care health information into the PCEHR*

3: Barriers to Increasing Usage in Clinical Settings

The College has identified four main barriers to increasing the clinician usage of the PCEHR:

- Lack of trust in the clinical information in the current PCEHR system
- Lack of trust in the PCEHR's Operator¹⁴
- Lack of useability of the current PCEHR system
- Non-integration of the PCEHR in other health IT systems and clinician workflows

The following sections of this Response detail the identified issues and recommendations:

2: Use of the PCEHR by Health Care Professions in Clinical Settings

5: Key Clinician Utility and Usability Issues

¹⁴ Currently the PCEHR's Operator is Secretary of the Department of Health

4: Standards for Terminology, Language and Technology

The goal of semantic interoperability is essential in the long term. However, this is a difficult and complex path. There are global shifts occurring in the technology and standards community, driven by major investments in the US and Europe which will result in a significant period of transition in Australia. An analogy could be made with the VHS and Beta competition of 20 years ago. As then, the reality is that we will be operating with a mix of technologies for some time to come.

- a. Australia needs to keep in close touch with the international developments. More importantly, to assist both system purchasers and vendors, there needs to be an immediate focus on establishing an agreed national standards road map, with input from health informatics and standards experts and with significant clinical and industry and input to come up with a "real world" approach for affordably progressing towards that long term goal of full interoperability.

Recommendation 12: *That the Department lead the development of a National Health Standards Roadmap with input from health informatics, clinical and industry experts*

- b. At present, the current operation of the national e-health standard processes administered by Standards Australia¹⁵ is considered by many to be a failure. The following concerns have been raised:
 - the choice of priorities for the standards development process
 - the integrity of the standards process at several levels
 - the belief that the processes have ceased to be transparent
- c. Standards Australia technical committees consist mainly of volunteers. At present, the volunteers are under-represented, under-respected and the active participation is not reflective of the overall interests of the community. Together, all these factors have severely eroded the key foundation that underpins the PCEHR: consensus-based information exchange standards.
- d. There is also the persistent perception within the Australian health informatics standards community that the IT-014 standards processes as well as funding are currently driven by specific standards approaches and publication outcomes pre-agreed by either NEHTA or the Commonwealth Department of Health. This appears to be contrary to Standards Australia's charter as well as spirit and practice of consensus-based eHealth standards development worldwide.
- e. The College is concerned that any proposed course of action that comes out of this PCEHR Review will not be actionable while the standards processes as currently administered lack confidence, consensus and support amongst the many parties that are involved in the delivery of the PCEHR systems.

Recommendation 13: *That the Department review its contractual arrangements with NEHTA and Standards Australia to ensure that its support for the standards process is fully congruent with Standards Australia's consensus-based standards development guidelines.*

¹⁵ The relevant Standards Australia Committee is "IT-014 Health Informatics"

5: Key Clinician Utility and Usability Issues

The Department needs to ensure that the basic computing infrastructure needed to support good clinical care is in place at for core national services and in the acute sector. It also needs to foster implementation in the private sector in GP, specialist, private hospital and community care. Without systems in place that can accurately capture and seamlessly provide the information into the PCEHR as a natural by-product of their process of care, clinicians will continue to see the PCEHR as an "bolted-on imposition" on their workflows. This "add-on" nature of the PCEHR and its "patchy" information content has also lead to the perception of unreliability and a mistrust of the information held within it.

The College wishes to outline some useability concerns and offer resulting recommendations:

- a. The PCEHR system is unusable for most clinicians. It is considered as "clunky", "full of add-ons" and unnecessarily adding to the information system work that clinical practices do. It is seen by many who have considered using it as "time consuming", "productivity-eating", etc. The revised PCEHR implementation should take these systems as examples.
- b. The PCEHR system does not reflect clinical reality.^{16 17}
- c. Patient diaries are included in the PCEHR design, but are not required to be read by clinicians; therefore the rationale for their inclusion is unclear.
- d. Usability experts have not being employed to analyse and evaluate the PCEHR.

Recommendation 14: *That the Department revise the PCEHR's clinician-faced functionality to ensure it can reliably and accurately automatically capture and provide the information and is fully integrated with clinician workflows*

Recommendation 15: *That the Department direct the PCEHR implementers to re-engineer its clinician-faced functionality and useability*

- e. Most clinicians do not understand the PCEHR system - a simple, concise and "plain-English" explanation should be available without reference to other information sources.
- f. EHealth and PCEHR education appears to have not been included in medical education frameworks including AMC accreditation). It may be a challenge to incorporate PCEHR training into medical education in timely manner. However, a template curriculum and/or series of plans for educators would provide helpful guidance.

Recommendation 16: *That the Department cause the creation of simple "plain-English" education materials for clinicians*

Recommendation 17: *That the Department cause the creation of a template curriculum and/or series of plans for educators*

Recommendation 18: *That the Department effect the inclusion of PCEHR education in medical education frameworks including AMC accreditation*

¹⁶ Fernando & Dawson, "The natural Hospital Environment: a socio-technical-materiality perspective DOI: <http://dx.doi.org/doi:10.1016/j.ijmedinf.2013.10.008>

¹⁷ Hannan T, Celia C, 2013, Are Doctors the Structural Weakness in the eHealth Building? Internal Medicine Journal 43 (2013), www.achi.org.au/docs/Are_Doctors_the_Weakness_in_the_eHealth_Building.pdf

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6: Key Patient Usability Issues

Concomitant with the clinician useability of the PCEHR is the useability by patients and consumers.

The College wishes to outline the following observations and concerns as well as its resulting recommendations:

- a. Anecdotal evidence indicates the assisted PCEHR registration processes currently in use do not provide individuals with sufficient information on its governance or how to use the system.
- b. Relevant organisations have received reports of vulnerable patients, such as the aged, being approached during medical care to register for the PCEHR, without addressing their expressed concerns.^{18 19}
- c. Contrary to patient/consumer expectations of a health record that is controlled by them, clinicians and others moderate patient/consumer input to the PCEHR. So in reality there is no real patient/consumer "Personal Control" of the PCEHR.
- d. Although included in the PCEHR, patient diaries are not required to be read by clinicians, which raises questions with patients and consumers.

Recommendation 19: *That the Department publish a simple outline of the entities, meta data and rules that govern the privacy and security of the personal information within the PCEHR*

- e. Patients have expressed concern about what happens to information about their health in the PCEHR, in particular that potentially embarrassing information is leaked or they are "spammed" by healthcare companies.²⁰
- f. Patients believe that they may have to rely on private court action to rectify complaints etc satisfactorily and do not often have these resources.

Recommendation 20: *That the Department improve the privacy controls and regulations for patient health data in the PCEHR*

Recommendation 21: *That the Department improve the remedies available to patients/consumers privacy controls and regulations for patient health data in the PCEHR*

Recommendation 22: *That the Department publish a simple outline of the entities, rules and processes that govern the privacy and security of the personal information within the PCEHR*

¹⁸ Refer to Australian Privacy Foundation "Consumers FAQ" www.privacy.org.au/Resources/AS-PCEHR-Cons.pdf

¹⁹ Refer to Australian Privacy Foundation "Clinicians FAQ" www.privacy.org.au/Resources/AS-PCEHR-Clin.pdf

²⁰ See www.telegraph.co.uk/health/healthnews/10250585/Jeremy-Hunt-plans-sale-of-confidential-patient-medical-records-to-private-firm

7: Suggested Improvements to Accelerate Adoption

The College has identified six main improvements that it believes will increase adoption of the PCEHR:

- Rectify the non-effective and in some cases poor consultation input to the PCEHR developers.
- Clarify the purpose of the PCEHR, determined by the goals and objectives to be achieved
- Initiate a redesign of the PCEHR based on effective consultation with clinicians taking into account their expectations balanced with the expectations of patients and consumers
- Amend the PCEHR Act 2012 and/or the relevant Regulations and Rules to remove any concerns by clinicians, patients and consumers
- Re-establish standards processes that are fully congruent with Standards Australia's consensus-based standards development
- Create a simple outline of the entities, meta data and rules that govern the privacy and security of the personal information within PCEHR

The following sections of this Response detail the recommendations to accelerate adoption of the PCEHR:

- 1: Experience on the Level of Consultation with Key Stakeholders during PCEHR Development
- 2: Use of the PCEHR by Health Care Professions in Clinical Settings
- 4: Standards for Terminology, Language and Technology
- 5: Key Clinician Utility and Usability Issues
- 6: Key Patient Usability Issues

8: Further Comments and Recommendations

The PCEHR as a model of effective clinical information management and decision support is poorly designed and has an implementation plan that sits in opposition to the implementation of all complex human decision making systems both in health and in other industries. It fails to address the significant socio-technical human interactions that are critical to the success of a nationwide implementation. It lacks the flexibility to be adapted across the health care environments and on current evidence has been significantly exclusive of those who function at the centre of clinical information management in the current health care environment i.e. clinicians. On this point PATIENTS are now considered to be “clinicians” in their own right and must have effective communication tools both “e-” and “non-e” to share information about their care if we are to improve care delivery. This latter concept was clearly described by Professor Larry Weed in 1989. He stated, “We must think of the whole information system, and not just infinitely elaborate on the parts that interests us or fit into a given specialty. Patients do not specialise, and they or their families are in charge of all the relevant variables 24 hours a day, every day. They must be given the right tools to work with. They are the most neglected source of better quality and savings in the whole health care system. After all, they are highly motivated, and if they are not, nothing works in the long run anyway. They do not charge. They even pay to help and there is one for every member of the population.

The States and Territories of Australia should not be permitted to developed “their home grown or self-directed” e-health projects. The costs and inefficiencies of health care as well as poor outcomes requires a national standardised approach to care delivery. Any implementations within the States and Territories must comply with the national standardised guidelines as occurs in the aviation industry.

That the PCEHR address the issues that have been defined as the fundamentals for success of complex e-health systems. These are Collaboration, System Scalability and Flexibility the ability to create rapid form designs for end users (not in current PCEHR) and the use of Standards (the foundation for Interoperability). These systems can then support high quality research. The system must be web-based and be able to support intermittent connectivity and be of low cost i.e preferably free and open source. The most critical factor is that these systems must be clinically useful or they will not be used.

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