

eHR Bill submission

Please find attached two documents that I believe support my position:

- 1) the recent Australian review of their eHR system and
- 2) my 2012 submission to the public consultation, which makes clear that these are not newly expressed concerns.

I would also like to highlight the HA inspection report that I participated in at the request of PCPD:

http://www.pcpd.org.hk/english/publications/files/HA_inspection_report_e.pdf

In particular, I would highlight section 3.12/3.24 of the inspection report, where it was identified that a key element of the audit process according to the documentation simply did not exist, to illustrate my concern that oversight cannot be diminished in any way.

Please note that the Australians are now proposing to call their system My Health Record and NOT remove ANY patient control

I quote from the Australian review:

"The issue of patient control and the need for clinical confidence in the content has arisen in a majority of the submissions. The panel wishes to retain the engagement of the consumer as stewards of their own health and their own medical record while recognising the needs of the clinicians. The panel recommends a change in the focus of the medical record and the name to reflect more of a partnership between the clinician and the patient but it should be noted that MyHR will retain all of the personal controls that exist in the current PCEHR. "

Please note that the Australian review included the President of the Australian Medical Association, so that undercuts the claim of AMA opposition to patient control. □ □

My submission in 2012 makes it clear that patient control must be an essential element of the eHR system. This was at least the third time that I had made this point publicly to the eHR team, but they continued to resist this essential point.

Key points to be addressed by the eHR team now:

1. Patient control of who sees their personal medical records is essential. It is not good enough for the eHR team to say that this can be decided in Stage 2. I can accept implementing this in Stage 2, but it **MUST** be part of the plan. Transparency without control is meaningless as they should be well aware!
2. The process for review of research access of eHR records is largely undefined in the legislation and there are no guarantees that the membership of the review board will be competent to assess not only the medical research value but crucially the privacy risk that must be balanced against the research value for access to either anonymised or identified records. It is noteworthy that the Australian review specifies the wide range of professional inputs needed for their oversight committees, e.g. the proposed Privacy and Security Committee membership:

Chair to be Department of Health representative on
ACeH Board.

Representative of the Privacy Commissioner.

Consumer representative

General practitioner

Medical specialist

Medico-legal representative

Medical insurer representative

Software security expert

3. The PD(P)O controls and PCPD oversight must not be diminished in any way

I would be happy to respond to any queries that the Panel might have.

Thanks

John Bacon-Shone

23 June 14



Review of the Personally
Controlled Electronic
Health Record

December 2013



Our Vision

The electronic health record for Australians, will be a reliable, secure and trustworthy source of key clinical information. It will facilitate efficient and effective treatment of patients by health practitioners and enable consumers to access and manage their own health records in cooperation with their health providers to improve care. It will respect individual privacy but be clinically valuable to all areas of the health care industry. Interaction with the electronic health record will be highly automated and form a natural part of clinical workflows. The value of sharing health information electronically between healthcare professionals, will be demonstrated by enhanced efficiency and effectiveness of the delivery of healthcare, reduced hospitalisations and ultimately lives saved.



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Acknowledgements

The Panel would like to recognise the significant contributions by many organizations, groups and people who have built the foundations of an electronic health record system for all Australians. Establishing a system of this magnitude as witnessed in many Countries across the globe is highly complex and faces many challenges. Significant investments by Governments, associations, business, and individuals has seen solid progress in preparing the foundations of this National Asset.

The National Electronic Health Transition Authority (NEHTA), it's board and advisors, the Department of Health Federally and in our States and Territories, the many software providers, integrators, infrastructure providers, health professionals and the users themselves have been significant in developing the key foundations to a National digital health infrastructure.

Further, this report reviewing the Australian PCEHR is informed by the combined insights from many organisations and people who contributed their ideas and time to the review, through written and oral submissions. The Panel's task of distilling these insights into a series of recommendations, would not have been possible without the obvious experience, enthusiasm and wisdom of these contributors.

The Panel would especially like to thank:

- The Department of Health for their support of the review and quickly providing us with the background information, data and insights.
- Over 80 organisations and associations that responded to a request for information to support the review and also managed to provide succinct responses in only two weeks.
- The many individuals who responded to our requests for follow up interviews and meetings or phone calls without notice.
- A team of Health and IT professionals from the Northern Territory who shared their eHealth journey with us.



Foreword

This document is a collection of recommendations made by the review panel established by the Federal Minister for Health, The Honourable Peter Dutton, Member of Parliament, in relation to the Personally Controlled Electronic Health Record (PCEHR).

The review has been completed in six weeks which has only been made possible by the access to significant and well thought out work that has gone into researching both eHealth and the PCEHR by others to date. When evaluating this work it is also assumed that readers will be familiar with the following publications:

- National Electronic Health Transition Authority (NEHTA) - *Concept of Operations* (Version 0.13.6 – April Release)
- Department of Health- *Concept of Operations: Relating to the introduction of a Personally Controlled Electronic Health Record System* (September 2011 release)
[http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/PCEHRS-Intro-toc/\\$File/Concept%20of%20Operations%20-%20Final.pdf](http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/PCEHRS-Intro-toc/$File/Concept%20of%20Operations%20-%20Final.pdf)
- NEHTA - *Strategic Plan (2011-2012)* <http://www.nehta.gov.au/about-us/our-strategy>
- Department of Health - *The Personally Controlled Electronic Health Records Act 2012 and the associated Personally Controlled Electronic Health Records (Consequential Amendments) Act 2012* were assented to on 26 June 2012.
<http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/pcehr-legals#.Uq0nDaW0TLQ>
- Department of Health - *Practice Incentive Program – eHealth incentive guidelines August 2013*. <http://www.medicareaustralia.gov.au/provider/incentives/pip/forms-guides.jsp#N10068>
Last accessed December 13, 2013
- NEHTA - *Annual Report 2013*. <http://www.nehta.gov.au/media-centre/news/470-nehta-s-annual-report-2012-13-is-now-available>
- *National eHealth Strategy Summary December 2008*. Australian Health Ministers Conference. http://www.ahmac.gov.au/cms_documents/National%20E-Health%20Strategy.pdf
- *Healthcare Identifiers Act 2010*. <http://www.comlaw.gov.au/Details/C2010C00440>
- *Healthcare Identifiers Act and Service Review – Final Report – June 2013*.
<https://www.health.gov.au/internet/main/publishing.nsf/Content/hlth-id-act-srvc-review-container>
- *Privacy Act 1988* <http://www.comlaw.gov.au/Details/C2012C00414>

The report is structured to enable the reader to quickly review a summary of the 38 recommendations that are identified across 8 key areas. These recommendations are made in response to 14 commonly identified concerns extracted from the 86 submissions and many interviews. The Panel notes the passion and enthusiasm that all health industry professionals and consumer rights advocates, have shown in responding to this work. The overwhelming belief of nearly all respondents is that an electronic health record is a critical investment for Australia that we should all support. Most agree that it is worth the effort to find a way through the many challenges, conflicting requirements and varying but valid opinions to continue with the build of this important national asset.



Terms of Reference

On November 3, 2013 the Federal Minister for Health The Hon Peter Dutton MP announced a review of the Personally Controlled Electronic Health Record system (PCEHR) by a small Panel of Health and IT experts. The panel has conducted a review of the PCEHR, dealing with implementation, uptake and including, but not limited to the following:

- The gaps between the expectations of users and what has been delivered
- The level of consultation with end users during the development phase
- The governance and control systems that were applied during the development and implementation phases
- The level of use of the PCEHR by health care professionals in clinical settings
- Barriers to increasing usage in clinical settings
- Key clinician utility issues
- Key patient usability issues
- Work that is still required including new functions that improve the value proposition for clinicians and patients
- Drivers and incentives to increase usage for both industry and health care professionals
- The future role of the private sector in providing solutions
- The policy settings required to generate private sector solutions
- The governance arrangements to set the ongoing future directions of the PCEHR in the context of other eHealth initiatives (and timing of changes).



Introduction

The PCEHR is an online summary allowing healthcare providers and hospitals to view and share an individual's health information, including diagnoses, allergies and medications. The PCEHR was commissioned in July 2012 and has had over 1 million consumers register to use it following a recruitment drive in mid 2013. (Figure 1)

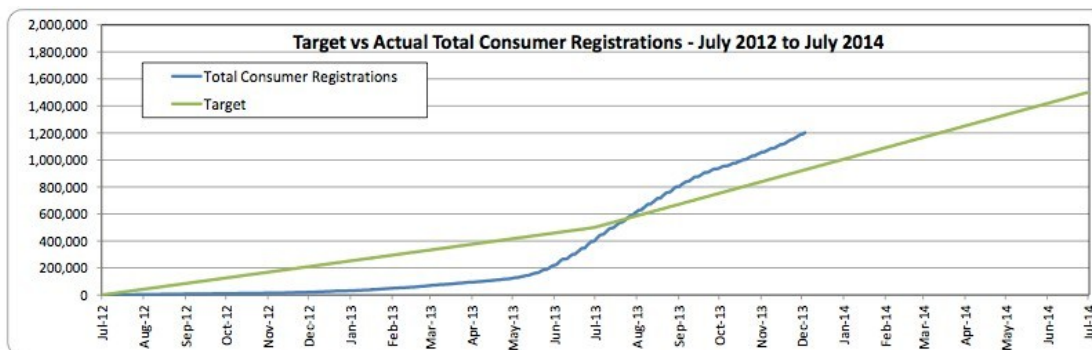


Figure 1 : PCEHR Operations Report Dec 3 Department of Health

As might be expected based on global experience, adoption and utilisation was slowly growing but appears to have plateaued despite increasing consumer registration (Figure 2). This level of utilisation is most likely the consequence of the issues raised by the stakeholders around the usability and clinical value of the PCEHR in this report.

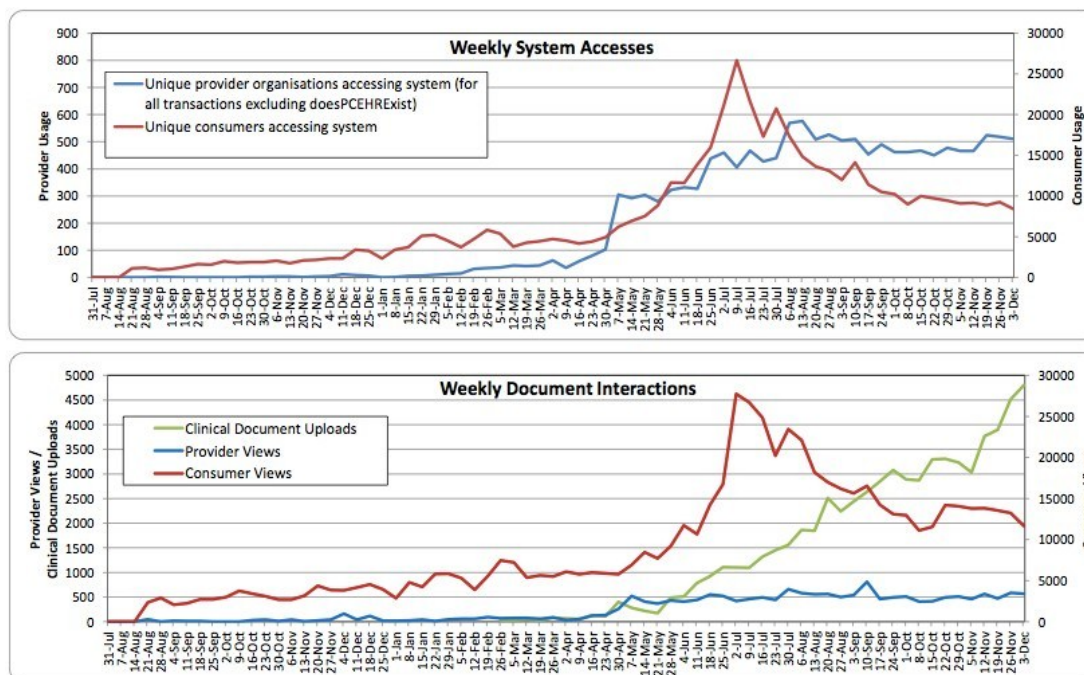


Figure 2 : PCEHR Operations Report Dec 3 Department of Health



The Panel notes that the PCEHR is regarded as one of a number of important foundations of the broader eHealth strategy. As per the Deloitte findings in their work to refresh the eHealth strategy (2013), the Panel supports the view that the foundational work in eHealth undertaken to date has provided Australia with a strong national infrastructure base that is now in place and starting to be used by both public and private health providers. Stakeholders have positively endorsed infrastructure including the national Health Identifier (HI) service, National Authentication Service for Health (NASH), Secure Messaging Delivery (SMD) Standard, and the National Product Catalogue (NPC).

“In addition NEHTA have progressed the development of a number of priority eHealth information specifications and standards, including clinical documents, terminologies and technical standards (e.g. Secure Message Delivery). A number of other high priority standards and related work products continue to be developed. The States and Territories have made very significant investments in the clinical and patient management systems that will be the key engines for implementation in the public hospital system. State and Territory health departments have progressed their investment in eHealth at different rates based on their own priorities but maintaining general consistency with shared national infrastructure and the 2008 strategy.”

eHealth Vision: Australians and their health care providers are connected through eHealth to up-to-date, accurate and reliable health information, enabling better engagement, access and services in healthcare.

Deloitte eHealth Working Group (EHWG) National eHealth Strategy for Australia Summary Strategy Report November 2013

The 2013 National eHealth Strategy has been commissioned by the Council of Australian Governments (CoAG) Standing Council on Health (SCoH) with a view to refreshing and extending the 2008 National eHealth Strategy.

The 2008 National eHealth Strategy built upon collaborative action commenced several years earlier by Australian governments to establish core foundational elements that would support the implementation of eHealth across Australia. The case for collective action at the national level was founded upon a view that the establishment of national standards was critical to ensuring there was no ‘rail gauge’ problem in eHealth in Australia, and that the cost and public benefit of this justified national coordination of this activity.

The core strategy elements can be summarised as follows.

- Operating and completing the foundations for eHealth encompassing shared and/or critical standards and infrastructure. This is the national infrastructure that should be developed once and used collaboratively across the country;
- Ensuring that providers and individuals are focused on using beneficial solutions in high priority domains such as at risk patients (Aboriginal and Torres Strait Islander peoples, chronic care patients, older Australians, mothers with newborns), medications



management, care coordination and access as the core driver. Health care practice will be safer and more efficient, and care better managed as a result;

- Achieving meaningful use of eHealth solutions, tools and infrastructure through focused engagement and support of key Australian care providers and consumers. Care providers are considered the key to meaningful use and will provide leadership in the adoption of eHealth care practices; and
- Governing for outcomes to drive commitment and collaboration where required and the alignment of priorities to achieve faster and more effective implementation of the national eHealth work program.

If these strategy elements are done well and are executed in a coordinated way across the nation, there is a significant international body of evidence to suggest that the effective implementation of eHealth will materially help improve the sustainability of the Australian health care system through:

- Creating capacity in the health system through enabling providers to more efficiently access and share the information needed to deliver reliable and high quality coordinated care across different parts of the health sector;
- Moderating the demand for services by giving consumers the tools and the quality of information required to enable them to more actively participate in self-care and remain in the community
- Improving the accessibility of health care services for all Australians, especially the disadvantaged and those living in rural and remote communities, through improved access to electronic information and service delivery; and
- Reducing the unit cost of delivering health care by providing care providers with the tools and information required to make improved treatment decisions and to reduce the incidence of adverse events and unnecessary or duplicated services.

Deloitte eHealth Working Group (EHWG) National eHealth Strategy for Australia Summary Strategy Report November 2013

Health Care Costs

Expenditure on health in Australia was estimated to be \$140.2 billion in 2011-12, up from \$82.9 billion in 2001-02. This expenditure was 9.5% of GDP in 2011-12, up from 9.3% in 2010-11 and up from 8.4% in 2001-02. The estimated recurrent expenditure on health was \$5,881 per person.

Governments funded 69.7% of total health expenditure, a slight increase from 69.1% in 2010-11. The largest components of health spending were public hospital services (\$42.0 billion, or 31.8% of recurrent expenditure), followed by medical services (\$23.9 billion, or 18.1%) and medications (\$18.8 billion, or 14.2%).

AIHW 2013. Health expenditure Australia 2011-12. Health and welfare expenditure series 50. Cat. no. HWE 59. Canberra

The Australian Government's 2010 Intergenerational Report estimates that Australian public sector spend on health care will increase approximately fivefold in today's dollars from now until 2050.



Booz and Company estimate that over \$A7 billion in direct costs could be saved annually by digitizing the healthcare sector and that those cost savings would also reflect substantial improvements in the customer experience with millions of hospital visits and admissions avoided each year. Many of the issues Booz identified are consistent with the feedback received by the Panel across all stakeholders.

Efficiency benefits will be significant...



Direct benefits from digitizing the healthcare sector can be measured – the challenge is realization

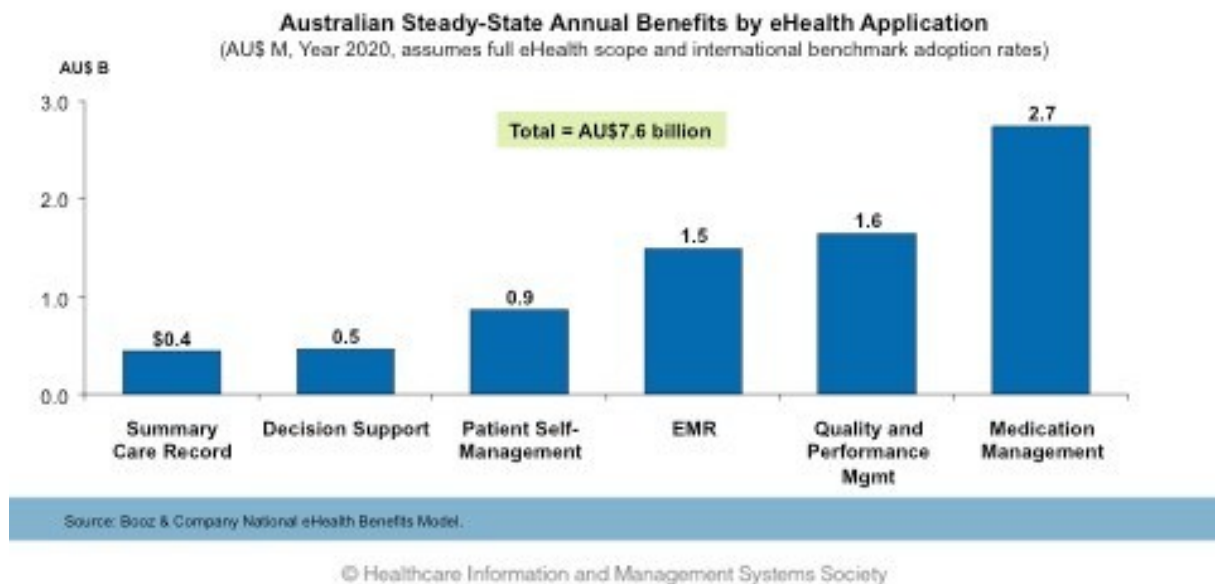


Figure 3 - courtesy of : Professor Mukesh Haikerwal and Chris Bartlett Booz and Company from their presentation "Using 21st Century Tools to overcome the 'fear of frying' and build success" 2013

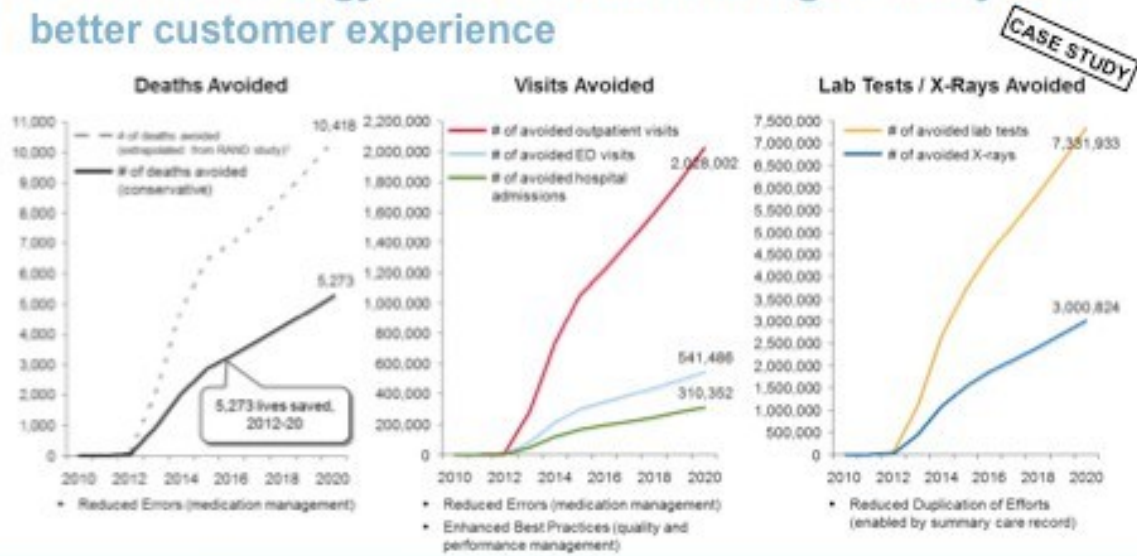


...and the benefits extend to effectiveness...



DIGITAL Healthcare
Week 2013
ORGANISED BY HIMSS ASIA PACIFIC

Health technology also contributes to significantly to a better customer experience



Source: Booz & Company National eHealth Benefits Model.

© Healthcare Information and Management Systems Society

Figure 4 - courtesy of : Professor Mukesh Haikerwal and Chris Bartlett Booz and Company from their presentation "Using 21st Century Tools to overcome the 'fear of frying' and build success" 2013



...however classic issues of change management create a barrier for fast and effective outcomes.

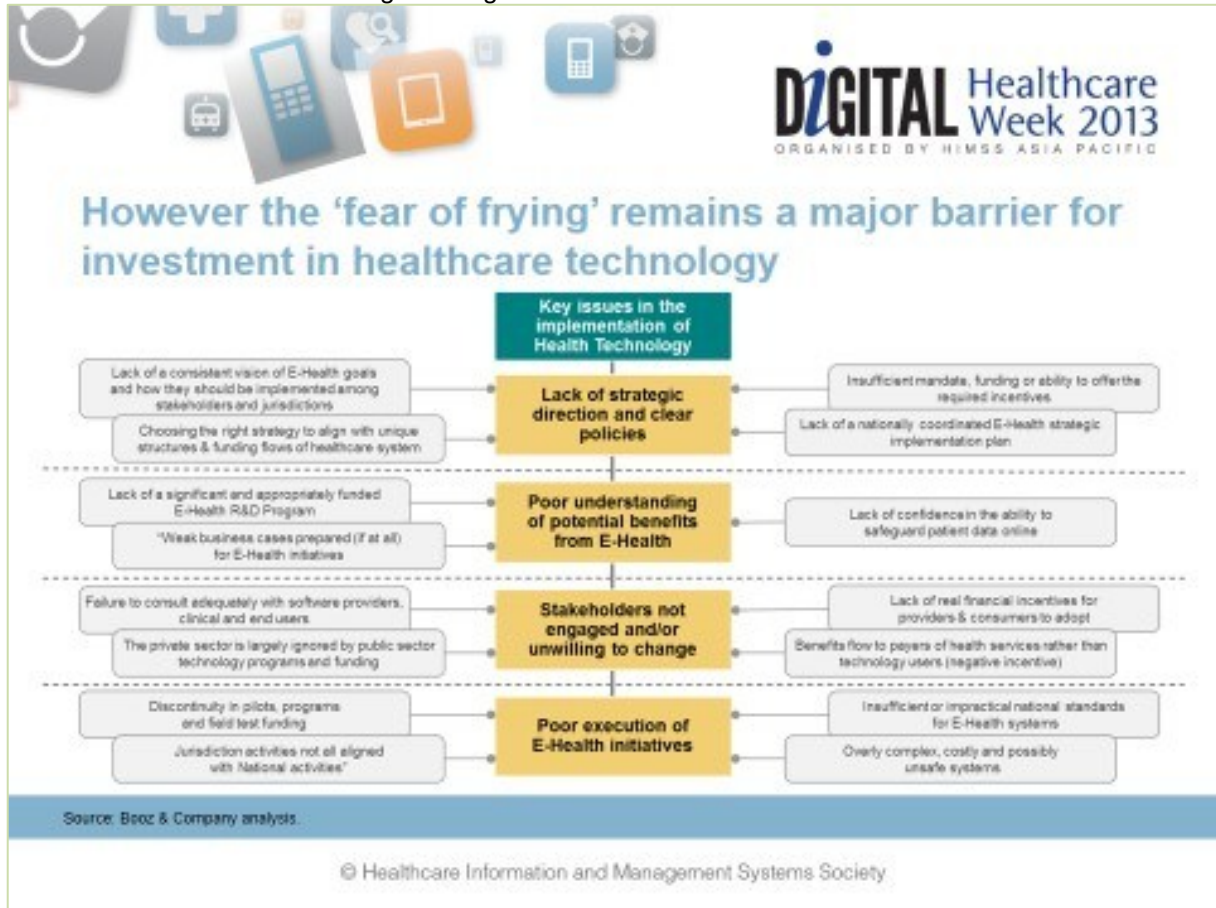


Figure 5 - courtesy of : Professor Mukesh Haikerwal and Chris Bartlett Booz and Company from their presentation "Using 21st Century Tools to overcome the 'fear of frying' and build success" 2013

This report makes a series of recommendations based on the stakeholders feedback, analysis of relevant facts and assessment of the Panel. The Panel finds that an electronic health record remains a critical part of the future Health infrastructure for Australia and with the recommended changes in the PCEHR will help accelerate the potential benefits identified by the 2008 eHealth Strategic Plan to provide more effective and efficient healthcare for all Australians.



Review Panel

Richard Royle BA MHA

Executive Director, UnitingCare Health

Richard has 35 years experience in the healthcare industry and is currently Executive Director of UnitingCare Health in Queensland, incorporating 5 private not-for-profit hospitals totalling over 1,000 beds, and employing approximately 4,000 staff. These hospitals include The Wesley and St Andrews in Brisbane, plus hospitals on the Sunshine Coast and in Maryborough and Hervey Bay. Richard has played a key role in setting UnitingCare Health's growth strategy. The group is also building a new 100 bed private hospital in Hervey Bay which will be Australia's first fully integrated digital hospital. He has held several other senior roles in healthcare organisations, including public and private hospitals as CEO, in New South Wales and Victoria. Richard is an Adjunct Associate Professor at Queensland University of Technology in Health Management. He is currently Vice-President of the Australian Private Hospitals Association and Chairman of their Policy and Advocacy Committee. He is also Deputy Chairman of the HESTA Superannuation Fund.



Dr Steve Hambleton MBBS FAMA

President, Australian Medical Association

Dr Steve Hambleton was elected Federal President of the Australian Medical Association (AMA) in May 2011, after serving a two-year term as Federal Vice President. Dr Hambleton was President of AMA Queensland in 2005/2006 and an AMA Federal Councillor. He served on the AMA Council of General Practice at a State and Federal level for more than 10 years. Dr Hambleton was the AMA representative on the National Immunisation Committee from 2006-2010, and was a member of the Pharmaceutical Benefits Advisory Committee for two years until 2009. He has been a member of the AMA Taskforce on Indigenous Health since 2006 and is currently the Chair of the Taskforce. Dr Hambleton is a member of the Clinical Care Standards Advisory Committee of the Australian Commission on Safety and Quality in Health Care Member



Andrew Walduck BBIS

Chief Information Officer, Australia Post

Andrew Walduck joined Australia Post in January 2012 with a key focus of evolving its Information Technology and business capability to meet the needs of a corporation responding to digital disruption and undergoing significant change as part of its strategy.

Andrew's career spans more than 20 years in Information Technology and includes technology roles in global corporations such as Accenture, where he was Partner in the Communications and High-tech Practice and prior roles at IBM. Prior to joining Australia Post, Andrew held a CIO role in the Corporate Division at Tabcorp. Andrew has a passion and expertise in using technology to provoke business change, building valued business relationships, leading and managing transformational programs and in implementing digital solutions that grow an organisations business in new products and services. Andrew also has a passion for growing and developing talented teams that deliver great business results.





Summary of Findings

The Panel has spoken with and received responses from many interested stakeholders of the PCEHR. Overwhelming support was found for continuing the path of implementing a consistent electronic health record for all Australians. A change in approach however is needed to correct early implementation issues and to review the strategy and role that a shared electronic health record plays in a broader system of health care. Future focus must see the electronic health record (and associated technical and data foundations) as a fundamental element of our future Health infrastructure and it is the Panel's view that with intervention and correction, the investment will realise great value for the health industry over time.

The value of having a personal health summary to share with selected health professionals will be that relevant information is available at the right time for the right people. Improved access, speed and accuracy of health information will benefit health providers, consumers and Government to deliver greater efficiency, less duplication and waste, safer, faster consultation, greater options for location of health provision and mobility of patients, greater consumer choice, and ultimately better health service delivery overall.

There is strong international evidence that data aggregation and management has led to better outcomes and is likely to lead to similar benefits for health care in for Australia.

Kaiser Permanente, an integrated managed care consortium, based in Oakland, California, United States have developed evidence based care protocols (2500) that result in better outcomes from the data they have collected over the last twenty years. They believe that their \$US4B investments in eHealth have paid significant dividends. Sepsis is the number one cause of death in hospitals in the US and they have reduced their death rates by 66%. They have also reduced their death rate from stroke by 40%, bone Fractures by 40% and heart attack by 50%.

They have reduced their pressure ulcer rates from 4% to in some hospitals now 0%. They have the best HIV care in the country.

Kaiser's Principle is simple:

GOOD INTENTIONS + GOOD DATA = GOOD OUTCOMES.

Facts taken from: "Don't Let Health Care Bankrupt America. Strategies for Financial Survival". George C Halverson. 2013

The PCEHR is in its early stages of implementation (when compared to other global electronic health record implementations) and therefore this review is timely. Significant investments of time and capital have been made to establish the PCEHR and the feedback has come when collectively we have an opportunity to assess, learn and adjust to what the users of this infrastructure need to get the most from this investment.



Key Concerns From The Submissions

Following is a list of key and repeating concerns that were identified through submissions from invited groups, unsolicited feedback by interested parties, and a series of interviews with key stakeholders:

1. The divide between clinicians who are concerned with data accuracy under a patient controlled model and consumers and others who identify the personally controlled nature of the electronic record as fundamental.
2. Opt-in versus opt-out of consumers – significant challenges with the opt-in process to date, including a lack of focus on those in most need of an electronic health record (such as those with chronic medical conditions or those living in remote areas).
3. Value proposition for users until data sets are populated with clinically usable information.
4. Value proposition for users if data sets are unreliable or incomplete, and the liability and indemnity that flows from this.
5. Usability of the system at all stages of engagement from registration to reinstatement and the process for identifying and addressing usability issues. This includes ensuring system interaction is designed to be part of a standard workflow of events.
6. Change Management in particular the lack of education and training modules and an effective test environment for software developers and integrators.
7. The Governance processes around the PCEHR did not adequately represent the industry and were overly bureaucratic in nature and did not effectively balance the needs of government and private sector organisations.
8. Engagement, effective consultation and buy in from a number of stakeholder groups. For example the private sector in general including private hospitals, medical specialists and software vendors.
9. The need for effective support for users of the system via the web, mobile applications and over the phone.
10. Incentives and the effective use of financial support to offset initial and ongoing costs of implementation for organizations and clinicians.
11. The lack of integration between current systems, a single sign on and ease of navigation between health applications are significant inhibitors to use of the PCEHR.
12. The level of incentives and support for investment by software vendors is not perceived as relevant or effective.
13. Privacy and security of records remain a priority for all users and an understanding of how the privacy and security works for consumers and practitioners.
14. Development of and compliance with standards are critical for adoption of any federated system or process. Common terms and language, IT protocols and report structures will improve integration and application however standards should be developed with current workflows in mind and using accepted and tested methods for development.



Summary of Panel Recommendations

The Panel invited about 200 organisations and individuals that had previously made formal submission regarding the PCEHR to update their responses and provide feedback on the implementation of the PCEHR to date, including the technology, process and Governance surrounding the system. We received 86 responses and conducted many interviews across the Country. The Panel has distilled and aggregated the feedback and information into common and repeating messages from the respondents. More detail on the themes from stakeholder feedback is in Addendum 3.

Having read all feedback from interested groups and individuals, studied and endorsed the need, benefits and case for a shared health summary and considered all the views and ideas, the Panel focused on those elements that would:

- Support realizing the benefits sooner.
- Focus on improving the value proposition for users.
- Improve reasons for the significant volume of stakeholders in the private sector to also invest and embrace the system.
- Improve governance to better align the needs of the target users with the delivery of function.
- Aim to minimize ongoing costs to develop and maintain the system, whilst recognizing the need for ongoing investment.

All suggestions that were not marked confidential will be made available to the relevant ministerial, departmental and advisory teams with our summaries to support ongoing change and further collaboration.

The Panel recommends the following key actions in relationship to realizing the benefits of the PCEHR:

1. **Rename** the Personally Controlled Electronic Health Record (PCEHR) to My Health Record (MyHR).
2. **Restructure** the approach to governance, dissolve NEHTA and replace with the Australian Commission for Electronic Health (ACeH) reporting directly to the Standing Council on Health (SCoH).
3. **Establish** a Clinical and Technical Advisory Committee to ACeH.
4. **Establish** a Jurisdictional Advisory Committee to ACeH.
5. **Establish** a Consumer Advisory Committee to ACeH.
6. **Establish** a Privacy and Security Committee to ACeH.
7. **Establish** a taskforce to transition arrangements between the current governance structure and the one recommended in this report.
8. **Maintain** the Independent Advisory Council (IAC) with an altered reporting line, direct to the Federal Minister for Health.



9. **Commission** an external review of the function and roles in the eHealth section of the Department of Health, Department of Human Services (DHS) and NEHTA to assess duplication and alignment with mandates
10. **Establish** a regulatory body that monitors and ensures compliance against eHealth standards that are set and maintained by ACeH.
11. **Centralise** the system operation of the MyHR to the Department of Human Services (DHS), under contract from ACeH. DHS should run all MyHR related infrastructure services and maintenance, performance reporting, contact centres, management of NASH, and the Health Identifier service. ACeH to work with DHS to assess which components of the service should be contracted out to private partners, with DHS remaining the overarching government department responsible for service delivery.
12. **Establish** a clinical systems capability (group) within the Department of Human Services (DHS) to integrate and coordinate improvement to all health systems and platforms.
13. **Transition** to an 'opt-out' model for all Australians on their MyHR to be effective from a target date of 1st January 2015. This recommendation is subject to the completion of the minimum composite of records (recommendation 21) and the establishment of clear standards for compliance for clinical users via the Privacy and Security Committee.
14. **Commission** a technical assessment and change management plan for an opt-out model to be undertaken in early 2014 in order to determine requirements and identify costs for a model change.
15. **Require** an annual report from the Privacy and Security Committee on:
 - a. the number of individuals who have opted out of the MyHR
 - b. the number of documents that have access controls changed by category
 - c. meaningful use and adoption by the profession
16. **Commission** an Information Security Risk Assessment of the end-to-end flow of consumer information to and from the MyHR platform. Findings and mitigation actions to be reviewed and agreed by the Privacy and Security Committee
17. **Clarify** that the MyHR is a supplementary source of information that may, but does not always need to be, used by clinicians in caring for their patients.
18. **Develop** and conduct an education campaign for consumers and clinicians about the impact of the change to an opt-out process and the strength of security and privacy in the system.
19. **Expand** the existing Australian Medications Terminologies (AMT) data set to include a set of over the counter (OTC) medicines.
20. **Widen** the existing National Prescribing and Dispensing Repository (NPDR) to include the expanded set of over the counter (OTC) medicines.
21. **Implement** a minimum composite of records to allow transition to an opt-out model by a target date of 1st January 2015 inline with recommendation 13. This will dramatically improve the value proposition for clinicians to regularly turn to the MyHR, which must initially include:
 - Demographics
 - Current Medications and Adverse Events
 - Discharge summaries
 - Clinical Measurements



22. **Work** should proceed to allow the integration of diagnostic imaging and pathology into MyHR but their delivery dates should not delay transition to opt-out
23. **Implement** a standardised Secure Messaging platform for the medical industry, prioritising support for standards compliant platforms.
24. **Expand** the Secure Messaging strategy to include exchange of secure communication between the medical industry and consumers to facilitate improved communications and workflow efficiencies.
25. **Review** the NASH platform with a view to evolving the platform to align with the recommendations for Digital Identity that is included in the Coalition's Policy for E-Government and the Digital Economy.
26. **Review** the current development program for the PCEHR and deliver prioritised usability improvements based on user centred design principles in partnership with industry. The usability improvements to be designed to complement everyday workflows.
27. **Add** a flag to the clinical author to identify if their patient has restricted or deleted a document in their MyHR to facilitate a discussion on the clinical impact.
28. **Notify** the consumer via an SMS message when their MyHR is opened or used by default. For patients that do not have a mobile number, a message will not be sent, however mobile contact number should be requested as part of the standard information for a customer's profile.
29. **Enable** a single sign-on capability that enables simplified usability as users of the systems are able to seamlessly pass from one system to another.
30. **Evolve** education, training and implementation programs to engage industry associations in the design and delivery of programs. This includes implementation of online training tools, including provision of a simulated MyHR environment to support required training volumes.
31. **Immediately** update the MyHR strategy to actively enable decentralisation of information across multiple data repositories, with information being linked using the Healthcare Identifier (HI).
32. **Reset** the policy standards and frameworks necessary to enable interoperability, in a decentralised model, plus commercial models that ensure providers can generate an acceptable return on the investments made in shared infrastructure.
33. **Prepare** a business case that defines appropriate methods of compensation for investment should be investigated that include one-off costs and/or transaction fee services for clinical access to records associated with integration of existing data sets into the MyHR.
34. **Introduce** by ACeH Board a new balanced scorecard of metrics that includes primary metrics (e.g. meaningful use metrics) and secondary metrics (e.g. leading indicators) that are aligned with the benefits and goals of the MyHR.
35. **Apply** governance principles of transparency of metrics and reporting to build confidence in the clinical relevance of information that is provided.
36. **Change** the ePractice Incentive Payment (ePIP) to introduce meaningful use metrics that incent contribution of clinical relevant information to the MyHR, including linking ongoing ePIP funding to actual usage of the MyHR.
37. **Commission** a scoping project to identify the options available to encourage further take up of electronic transmission of data by specialist medical and allied health professional practices and private hospitals.



38. **Alter** the Medicare Item number requirements from January 1st 2015, for health assessments comprehensive assessments, mental health care plans, medication management reviews and chronic disease planning items to require a copy of the information to be uploaded to the MyHR.

A COMPELLING CASE ON THE PRACTICAL APPLICATION FOR THE PCEHR RELATING TO THE COORDINATION OF HEALTH CARE

The coordination of a person's health care is an important factor in ensuring the best possible health outcomes. This is particularly true for those people who have seen several health professionals for the same health condition. Ensuring the correct information is passed between health professionals will serve to minimise errors and limit the possibility for symptoms to be overlooked. The coordination of health care enables a person to access the full range of services they need to treat their health condition.

In 2012-13, around one in six people aged 15 years and over (16.3% or 3 million people) saw three or more health professionals for the same condition. Females were more likely than males to have seen three or more health professionals for the same condition (18.6% compared with 14.0%).

The proportion of people who saw three or more health professionals for the same condition generally increased with age. Almost one in four people (23.6%) aged 75-84 years had seen three or more health professionals for the same condition, compared with almost one in ten (9.3%) people aged 15-24 years. Those who had a long term health condition were more likely to have seen three or more health professionals than those without a long term health condition (27.6% compared with 7.2%).

Of those who saw three or more health professionals for the same condition, 68.8% reported that a health professional helped coordinate their care. Of this group, the health professional most likely to coordinate the care was a GP (53.7%), followed by a medical specialist (29.6%) and then a nurse (6.4%). The coordination of care helped to a large extent for 69.0% of people, while 27.4% reported that it helped to some extent.

Those living in areas of most socio-economic disadvantage were more likely to report that a health professional helped coordinate their care compared with those living in areas of least socio-economic disadvantage (73.3% compared with 64.3%). Among those whose care was coordinated, those living in areas of most disadvantage were then less likely to report that the coordination of care helped to a large extent compared with those living in areas of least disadvantage (66.5% compared with 73.9%). Major cities were similar to other remoteness areas of Australia.

Among those who saw three or more health professionals for the same condition, 12.8% reported that there were issues caused by a lack of communication between the health professionals. Those living in areas of most socio-economic disadvantage were more likely to report that there were issues caused by a lack of communication between health professionals compared with those living in areas of least socio-economic disadvantage (13.8% compared with 10.3%). Those living in outer regional, remote or very remote areas of Australia were more likely to report that there were issues caused by a lack of communication between health professionals compared with those living in major cities of Australia (16.5% compared with 11.7%).

Australian Bureau of Statistics

Source(s): *Patient Experience Survey: Summary of Findings*



Recommendations In Detail

Naming of PCEHR

The issue of patient control and the need for clinical confidence in the content has arisen in a majority of the submissions. The panel wishes to retain the engagement of the consumer as stewards of their own health and their own medical record while recognising the needs of the clinicians. The panel recommends a change in the focus of the medical record and the name to reflect more of a partnership between the clinician and the patient but it should be noted that MyHR will retain all of the personal controls that exist in the current PCEHR.

As the adoption and embrace of the digital age accelerates the need to differentiate between digital and physical sources is losing its relevance. Digital interactions have now been mandated as the primary form of interaction for 80% of government services by 2017, and the revision of the name reflects a modern naming convention for digital services.

Recommendation:

1. **Rename** the Personally Controlled Electronic Health Record (PCEHR) to My Health Record (MyHR).

This section should be read in conjunction with recommendation 13 opt-out versus opt-in. MyHR will retain all of the controls that exist in the current PCEHR.



Governance

Effective and impactful governance is critical for any major investment program. Several factors are critical for building and maintaining a strong governance function. These include (but are not limited to):

- Selection of trusted personnel who will represent the views of the target audience and who have authority and accountability to act.
- Alignment of the governance body to an effective strategy.
- Transparency of operating performance to empower effective decision making.
- Appropriate framework and processes to effectively govern and coordinate investments.
- Decision making empowerment with a culture to act.
- Open and regular communications to all impacted audiences.

The review of the PCEHR has identified that whilst a governance structure has been in place within NEHTA, for the PCEHR in the context of eHealth it is in need of significant change as it does not have the confidence of the industry or audience that it is attempting to represent. Multiple factors have contributed to this including a significant broadening of the remit of NEHTA since its inception. A reset of this function is critical to ensure the Australian health industry can continue to evolve with a strong set of foundational capability that will enable operating efficiencies for all providers, whilst driving improved patient care benefits.

Given the scale and complexity of the national eHealth work program, Australian Governments should continue to play a lead role in directing and coordinating national implementation activities. However, the move from a focus on nationally shared eHealth infrastructure to meaningful use of eHealth solutions by care providers and consumers, argues the case for a more broadly based involvement in the governance process – particularly extending to clinical and patient communities and private sector health operators.

Key to strengthening the current governance arrangements will be the establishment of an eHealth entity (created through the transformation of NEHTA) that is focused on coordinating execution of the national strategy and the nationally funded eHealth work program. To perform this role it will be necessary for the eHealth entity to have a Board made up of key parties beyond Government representatives (including strong care provider and consumer representation) and to oversee the building of close working relationships across the public and private health sectors and with the health IT vendor community.

Deloitte : National e-Health Strategy for Australia November 2013

Review Findings

Currently the Board of NEHTA is predominantly comprised of the Directors General of State and Territory Health Departments plus the Secretary of the Federal Department of Health. This was appropriate in the early phases of development however, the board membership did not change to match the role expansion that has occurred.



Given the primary purpose of the Board, as identified on the NEHTA website, “is to lead the uptake of eHealth systems of national significance”, there are no stakeholders who are active users of the PCEHR on the current NEHTA Board.

Two Jurisdictions raised this issue as a concern and commented that they have very little direct engagement in the PCEHR. The Panel also notes that the National eHealth strategy document released in December 2008 identified seven governance principles in which it highlighted the need for appropriate stakeholder engagement and transparency.

A number of submissions received, including from Jurisdictions also highlighted the lack of transparency in the decision making process for the PCEHR within the NEHTA structure.

A common theme was that the stakeholders’ views were often sought and obtained, but in many instances these views (including those from Clinical leads and reference groups) perceived to be either overruled by the Commonwealth or lost in the NEHTA process.

“it remains perplexing that the output from all of these consultations were largely ignored by Government and by NEHTA in recent times”.

Quote – The Royal College of Pathologists of Australia Submission

A revised governance body needs to have relative independence from State and Federal Government departments to ensure it is balanced and represents the needs of multiple key stakeholders to facilitate the elements of eHealth delivery by a healthy private sector in partnership with government provided services.

Setting of eHealth policy remains with the Minister for Health supported by the Department of Health.

eHealth strategy to implement those policies should rest with a new overarching governing body for eHealth.

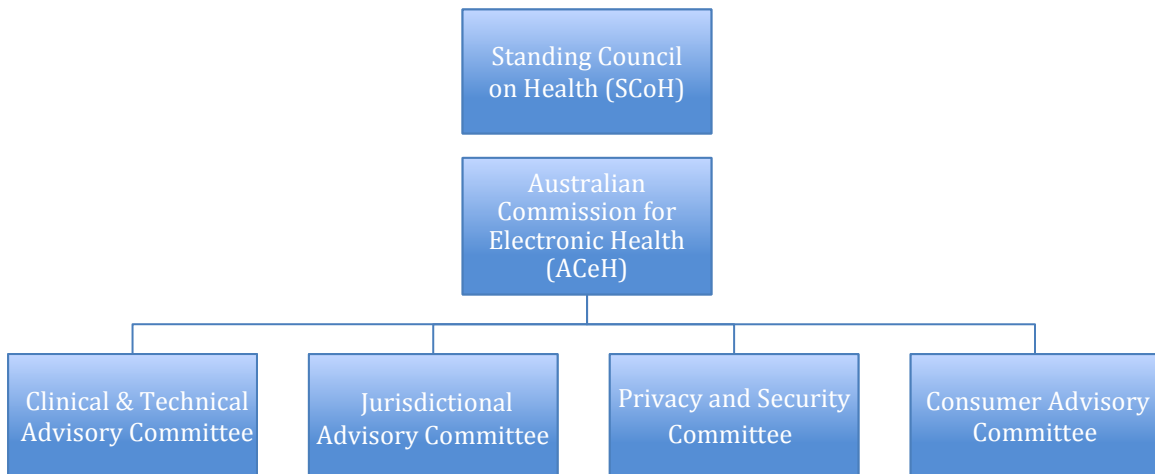
The Panel also notes that the role of System Operator, whilst centred on the Department of Health, has a number of sections of the PCEHR that are operated by other parties. Examples include the Department of Human Services being the operator of consumer and participant contact, the operator of the Health Identifier service, the National Authentication Service for Health (NASH) as well as the registration agent for the PCEHR. This split in responsibilities causes confusion in the market and requires consolidation.

Recommendation

2. **Restructure** the approach to governance, dissolve NEHTA and replace with the Australian Commission for Electronic Health (ACeH) reporting directly to the Standing Council on Health (SCoH).



- a) ACeH to be supported by four key sub-committees
- Clinical and Technical Advisory Committee
 - Jurisdictional Advisory Committee
 - Consumer Advisory Committee
 - Privacy and Security Committee



New Australian Commission for Electronic Health (ACeH)

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

- Development and execution of eHealth strategies (not just the MyHR) within the policy framework set by the Department of Health in conjunction with the Federal Minister for Health.
- Setting of implementation and funding priorities for eHealth initiatives
- Coordination and management of the government funding allocated to the implementation and management of eHealth in Australia.
- Provide and manage a vendor accreditation process to ensure appropriate integration with the MyHR.
- Provision of frameworks and requirements to allow value adding vendors to integrate with the MyHR.
- Monitoring of the performance, adoption and management of eHealth systems, including oversight of the Systems Operator.
- Providing open and transparent communication of the performance of the eHealth system.

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

The following composition is recommended:

- Independent Chair (nominated by the Federal Minister for Health)



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

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

Establish Advisory Committees to ACeH

ACeH will require a number of advisory committees in order to ensure appropriate consideration of issues under discussion. The following advisory committees are recommended in a revised governance structure:

3. Establish a Clinical and Technical Advisory Committee to ACeH

Bringing together clinicians and IT technical experts to:

- Ensure that eHealth applications enhance efficiency and effectiveness of clinical care.
- Advise ACeH on clinical and related technical functionality of the MyHR with the intention of increasing utility and functionality.
- Recommend priorities of development and implementation of eHealth clinical systems.
- Recommend investments in the MyHR.
- Advise on operational adjustments to be made to the MyHR system design based on experience with its use in clinical settings.
- Advise on measures to reduce the complex requirements for clinicians and practices to participate in the MyHR.

It is proposed that the clinical and technical aspects are brought together in one Committee to ensure that there is coordinated work to achieve practical clinical applications of IT systems. The panel recognises the benefits that have been shown following the recent introduction of the Clinical Usability Program, which has seen positive engagement between clinicians and NEHTA representatives. This proposed advisory committee builds on the positives of the CUP and adds technical input to ensure that silos are not built between clinical and technical expertise.



Proposed Membership

- ACeH Board member (General Practitioner).
- Specialist medical practitioner.
- Pathology representative.
- Diagnostic imaging representative.
- Nurse practitioner or registered nurse.
- Pharmacist.
- Allied health professional.
- Public hospital Chief Information Officer representative.
- Private hospital Chief Information Officer representative.
- Health software industry representative.
- Department of Human Services representative (as system operator).
- Member of the Consumer Advisory Committee.
- Rural doctor.

4. Establish a Jurisdictional Advisory Committee to ACeH

Proposed membership

- Chair to be the Chair of ACeH.
- Jurisdictional Health representatives (nominated by the Director General of each Jurisdictional Health Department).
- Federal Department of Health Representative.

Role

- To advise on all issues directly relating to eHealth to ensure national alignment.
- All key decisions of ACeH will require consultation and advice from this Committee.

5. Establish a Consumer Advisory Committee to ACeH

Proposed membership

- Chair to be the consumer representative on ACeH.
- Up to 3 consumers, representing different consumer groups.
- General practitioner
- Specialist medical practitioner
- Nurse practitioner or registered nurse
- Allied health professional
- Department of Human Services representative (as system operator)
- One member of this Committee to also be a representative on the Clinical and Technical Advisory Committee (to ensure crossover of information).



Role

- To ensure all stakeholders are being effectively engaged and communicated with.
- To recognise the interests of minority and special interest groups to ensure they are being effectively heard.
- To monitor, assess and advise the board on issues related to break downs in collaboration or barriers to better execution.
- Bringing together consumers and clinician experts to ensure that eHealth applications:
 - Facilitate consumer participation in their healthcare.
 - Enhance efficiency and effectiveness of clinical care.

6. Establish a Privacy and Security Committee to ACeH

Proposed membership

- Chair to be Federal Department of Health representative on ACeH Board.
- Representative of the Privacy Commissioner.
- Consumer representative
- General practitioner
- Medical specialist
- Medico-legal representative
- Medical insurer representative
- Software security expert

Role

- Responsible for examining legal and related issues regarding the MyHR including ownership, copyright, data privacy, confidentiality, security, liability, and formulating recommendations for the long-term legal framework as well as interim solutions to address these issues.
- Monitor clinical security and privacy issues and their resolution. This process should be transparent to build confidence in both consumers and health practitioners with reports on breaches of security and/or privacy being made public on a regular basis.
- Oversee the standards for security and privacy to which all clinical users of the MyHR must adhere. This can be along similar principles to the Royal Australian College of General Practitioners Privacy Principles that practices must adhere to in order to maintain accreditation.
- Facilitate protected reporting of privacy & security issues by users of eHealth systems.
- Provide an annual report to the Federal Minister for Health to ensure its transparency.

Transition Taskforce

7. Establish a taskforce to transition arrangements between the current governance structure and the one recommended in this report.

A dedicated taskforce (to be nominated by the Federal Minister for Health) will need to be established to create, cost and execute a transition plan to ensure that the current work being undertaken by the NEHTA Board is smoothly transitioned into ACeH and the appropriate sub-committees. This will



require close consultation with the Jurisdictional and Federal heads of Health Departments in order to maintain momentum on national strategies such as matching identifiers with public hospital files, and leveraging the current work in electronic medications in order to further progress the e-medicine framework for the MyHR.

8. Maintain the Independent Advisory Council (IAC) with an altered reporting line, direct to the Federal Minister for Health.

The current IAC has proved to be a useful forum for oversight of the PCEHR process. It is recommended that this body, with its existing membership, continues to operate under its terms of reference as identified in the IAC Charter (31 August 2012). However, the current reporting line to the System Operator (Department of Health) should be changed to the Federal Minister for Health to improve transparency.

9. Commission an external review of the function and roles in the eHealth section of the Department of Health, Department of Human Services (DHS) and NEHTA to assess duplication and alignment with mandates.

Given the proposed terms of reference for ACeH, and for stronger engagement with the private health software industry and an increased focus on implementation of the Technology and Data foundations in this report, an external review of the function and roles in the eHealth section of the Department of Health, Department of Human Services and NEHTA should be performed. The focus would be to optimise the operating functions and structure of both organisations and to remove any duplication. This review should be undertaken once implementation of this report's recommendations has commenced to support the design of ACeH.

10. Establish a regulatory body that monitors and ensures compliance against eHealth standards that are set and maintained by ACeH.

A current challenge in the eHealth industry is the inability to ensure compliance to agreed standards by software providers and for those standards to be agreed. This has resulted in a number of examples where it has proved exceedingly difficult to effect change in software suppliers to adapt their software in order to comply with industry driven standards. Combined with improved standards setting processes, the establishment of a regulatory body to monitor and ensure compliance to these standards by means of incentives and penalties will enhance Australia's ability to move forward more quickly in developing a fully interconnected electronic health record for all Australians. Software vendors and associations overwhelmingly support the need for better standards management. Vendors supported the notion that clear standards, appropriate incentives for clinicians and effective monitoring of compliance would accelerate integration and interface enhancements.

11. Centralise the system operation of the MyHR to the Department of Human Services (DHS), under contract from ACeH. DHS should run all MyHR related infrastructure services and maintenance, performance reporting, contact centres, management of NASH, and the Health Identifier service. ACeH to work with DHS to assess which components of the service should be contracted out to private partners, with DHS remaining the overarching government department responsible for service delivery.

Consolidate all Technical and Data Foundations (as defined in this document) and Commonwealth run MyHR related infrastructure services and maintenance, performance reporting, contact centres,



management of NASH and the Health Identifier service and contract the Department of Human Services to be the System Operator.

Document and review end-to-end clinical and industry workflows, with a view to implementing the Technical and Data Foundations in a way that either seamlessly integrates and/or improves the performance of these workflows for the clinicians and industry. The workflows and subsequent design to be developed ACeH in partnership with industry representation and DHS involvement. DHS, in conjunction with ACeH, to determine whether components of this service should be contracted out to the private sector, with DHS remaining the overarching Government department responsible for service delivery.

12. Establish a clinical systems capability (group) within the Department of Human Services (DHS) to integrate and coordinate improvement to all health systems and platforms.

This group will manage integration and enhancement of the Technical and Data Foundations (see recommendations 19-26, 29,31,32) that should be provided as a national capability, operated by the Commonwealth. Resources to be redeployed from existing Departments. It is envisaged that a number of the specialised or commoditised services will be contracted out to private enterprise to spread risk, tap into broader skills and knowledge bases. This group must also prove and be held accountable to have the expertise to manage significant systems related contracts with third parties to ensure that any sub contracts are managed effectively and competitively. Systems and processes that fall into this category are those where security and privacy are paramount, scale is significant and interoperability with other Commonwealth systems is significant.

As a principle the following tests should always be applied first before building new systems or capability:

- Will the function or resident data be put at risk if not managed by the Commonwealth?
- Does the capability exist in a jurisdiction today that would be fit for purpose and could otherwise be leveraged to build out this solution on behalf of all Australians (80% or greater fit)?
- Is there a commercial solution already in the Australian market that could cost effectively and preferably competitively be assessed?



Opt-in opt-out

“Considering the current stage of the PCEHR roll-out and the lack of meaningful usage of the record, CHF reiterates its view that the PCEHR system will be more successful if it is to be opt-out, rather than opt-in. Our extensive consultation with consumers, consideration of the positions of other key stakeholder groups and review of international experience support and consolidate this position.”

Quote – Consumer Health Forum Submission

The Consumers Health forum (CHF) has previously highlighted that there are a range of benefits that are likely to result from the implementation of an opt-out system, as opposed to an opt-in system, including:

Wider uptake of the system, increasing its value to health professionals and, consequently their willingness to use the system;

- ‘Healthy’ consumers who might not have signed up to the PCEHR under an opt-in system will be more likely to have a PCEHR, allowing access to health information which could be of particular value if they experience an illness or injury that necessitates acute or ongoing treatment;
- Vulnerable and disadvantaged consumers will not have to actively opt-in to the system, allowing them to share in the benefits without facing the potential obstacle of signing up;
- Mechanisms will still be in place to support consumer choice, as opting-out will remain an option for those who do not wish to participate, and other consumer access controls will also be in place.

There is international evidence from New Zealand and from the UK that provided safety and security issues are addressed that an opt-out model is well received. The summary care record rollout by the National Health Service in England contacted 45,997,228 people with an opt-out rate of just 1.4%.

This transitioning should take effect from 1st January 2015, following the establishment of the Privacy and Security Committee (see Recommendation Number 6) and the establishment of clear standards for compliance by all clinical users of the electronic health record. This will require legislative change and will also be dependent on the completion of the first stage of integration of the information that forms the recommended minimum data set. (See Recommendation Number 21)

Privacy and Security will be paramount, as will the need to ensure that quality data will be available at the time of turning to opt-out, as this will provide a positive start to meaningful use of the electronic health record.



The Privacy and Security committee will oversee security issues and independently and transparently report to the Minister for Health. Software and data repositories will need to meet minimum privacy and security standards to participate in MyHR.

There are already mandatory reporting requirements and significant fines for data breaches in relation to the PCEHR. These should be carried forward. As well as reaching minimum standards for privacy and security of information, Public and Private Hospitals, General Practice and a significant number of medical specialists are subject to accreditation processes that will support confidence in those minimum standards.

Recommendations

13. **Transition** to an 'opt-out' model for all Australians on their MyHR to be effective from a target date of 1st January 2015. This recommendation is subject to the completion of the minimum composite of records (recommendation 21) and the establishment of clear standards for compliance for clinical users via the Privacy and Security Committee.
14. **Commission** a technical assessment and change management plan for an opt-out model to be undertaken in early 2014 in order to determine requirements and identify costs for a model change.



Personal Control Versus Clinical Need for Complete Unedited Records

Many of the submissions have focussed on the benefits and drawback of patient control. The clinicians warn about lack of confidence in the medical profession and the users of the system regarding the inability to be confident that the record has not been altered or that key information has been left out.

The consumers and privacy advocates are concerned about the safety and security of their information and wish to retain the ability to influence what is contained on their records and who sees it. The Panel has reviewed the controls and permissions available and believe that these are comprehensive (ADDENDUM 2) but should be reviewed regularly by the Consumer Advisory Committee for additions or deletions based on use and changing needs.

“Consumers have told CHF that they want to actively participate in the management of their record, rather than passively enable providers to enter information.”

Quote - Consumers Health Forum (CHF) submission

“The experience of the initial roll-out of the PCEHR demonstrates that the overwhelming majority of consumers give blanket consent at registration for the full range of information to be uploaded and for data to be accessed by all relevant health professionals.”

Quote - Consumers Health Forum (CHF) submission

“We support people taking greater responsibility for their own health, and the PCEHR has the potential to assist with this, but patient control should not mean that the PCEHR cannot be relied upon as a trusted source of key clinical information.”

Quote – AMA Press release 26/11/2013

“Certainly it would be preferable if the system did not allow patient control, but if that is to remain, then we believe there should be a specific notice on the record that particular documents have been masked”

Quote - From an indemnity insurer



The Panel considered these views and the views of many others and recommends the transition to an opt-out model whilst preserving the current controls that empower consumers. (See Addendum 2)

This would mean that all Australians who have not opted in by the transition date will have an unpopulated (from a clinical perspective) record available for use. Consumers would be able to opt-out of using the record and have it hidden from both use and reading by anyone. The record can be reactivated by the consumer should they wish to opt-in at a later time. The record and content that existed when it was deactivated would be available once again.

For Australians, who do not opt-out, when there is a clinical interaction there will be an assumption of standing consent for events summaries and shared health summaries to be added to the record. Hospital discharge summaries, current medication and adverse event lists and eventually, diagnostic imaging and pathology would automatically populate the record (subject to appropriate clinical workflows). Consumers would be free to remove or restrict documents, as they are now, but the Panel recommends that a flag be set to indicate that a document has been hidden, which is only visible to the practitioner who authored or uploaded the document.

Such a flag would facilitate a discussion with the consumer about their concerns and allow for a discussion about the clinical impact of a document removal. The document author is currently always able to see (and remove) the document they created in discussion with the patient. The outcome of that discussion might be removal of the restrictions, a replacement of the document with an agreed “clinically appropriate but different” document or maintaining those restrictions that are now also informed by clinical judgment.

The panel noted that no medical records are complete (in either paper or electronic form) and that there are some people who legitimately do not want to share everything. The panel disagrees with the advice from many of the submissions that a flag should be able to be seen by all those who view the record as in the panel’s opinion it would be likely to result in emotional “blackmail” by providers attempting to seek disclosure of the hidden information.

The patient and practitioner choices built into the system mean that an individual’s MyHR may not contain up-to-date information or complete information about their health but it should improve over time. The PCEHR should be considered a source of supplementary information.

There will be more and more information available in the MyHR over time and it will be some time before a critical mass of information is available or participation in the MyHR becomes routine.

In order to understand and to mitigate the risk of interacting with the MyHR clinicians need to be reminded that they are not legally compelled to open and use the MyHR. Clinicians need to be confident that they will be meeting the appropriate professional standard if they make decisions, in good faith, based on information in the MyHR even if they turn out to be incorrect because a patient has removed or restricted access to data. As with other forms of clinical information clinicians are expected to meet appropriate professional standards when interacting with the MyHR, but that is unlikely to extend to opening each and every document for every patient. MyHR clinical interface



needs to be designed to present clinicians with easy access to important data that is relevant to the care being provided at the time rather than endless list of documents. Opening of a record in error or uploading a document in error if done in good faith should not result in sanction.

Use and adoption by the profession should be surveyed and reported by the Privacy and Security Committee so that practitioners are kept abreast of peer professional opinion in relation to participation in the MyHR. This should extend to beyond merely signing up for use but be measured by actual use.

The security and use of important and private consumer information is important to review and understand from an end-to-end process of how customer information is supplied to MyHR (ie: via Clinical Information Systems and other integrated software as part of standard workflow events) and also how information is obtained from MyHR and stored in interfacing systems. Compensating controls, standards and compliance requirements are mitigations that may be required to be implemented to deal with ensuring the ongoing confidence in the platform and how customer's information is protected. The Privacy and Security Committee will have ongoing responsibility for the development, and regular review of an Information Security Risk Assessment.

Recommendations

15. **Require** an annual report from the Privacy and Security Committee on:
 - a. the number of individuals who have opted out of the MyHR
 - b. the number of documents that have access controls changed by category
 - c. meaningful use and adoption by the profession
16. **Commission** an Information Security Risk Assessment of the end-to-end flow of consumer information to and from the MyHR platform. Findings and mitigation actions to be reviewed and agreed by the Privacy and Security Committee.
17. **Clarify** that the MyHR is a supplementary source of information that may, but does not always need to be, used by clinicians in caring for their patients.
18. **Develop** and conduct an education campaign for consumers and clinicians about the impact of the change to an opt-out process and the strength of security and privacy in the system.



Minimum Composite of Records

A common theme in the consultation process was the need for a minimum data set to make up a viable clinical record. Many of the submissions also pointed out that it was imperative for the data standards to be widely and universally adopted to allow the MyHR to function. The more clinically relevant material that was present within the MyHR the faster the rate of adoption and therefore the faster the return on investment will be.

“Unless certain core medical information was meaningfully available to treating practitioners, the PCEHR would provide no benefits above the current system and would be rejected by doctors.

From the AMA submission

“Through the survey, RACP members were asked to nominate three key changes to the current system which could lead to improvements in care. The largest share of respondents, 23 per cent, indicated the need for the PCEHR to be more comprehensive for example, with datasets that include pathology and imaging results, allied health and mental health reports and radiology results. “

From the Royal Australian College of Physicians submission

Deloitte eHealth Working Group (EHWG) National eHealth Strategy for Australia 2013 stressed the importance of completing the foundations of eHealth that have already been established including the Health Identifier service to accurately identify the individual to track their health information.

The existing Australian Medications Terminologies (AMT) should be expanded to include a set of over the counter (OTC), medicines and the Systematised Nomenclature of Medicine for Australia (SNOMED-CT -AU) should become universal to promote the use of a nationally consistent language when recording and exchanging health information.

Deloitte eHealth Working Group (EHWG) National eHealth Strategy for Australia Summary Strategy Report November 2013

These foundation elements have not yet been widely adopted and actively used enough and so accordingly it is also a recommendation in this report that there be a regulatory body that monitors and ensures compliance against eHealth standards such as these. (See Recommendation 10)

The minimum necessary data set needs to drive both improved patient outcomes and increased clinical utility. Current medications and adverse events are the first elements to meet this requirement.



The PCEHR Value Model suggests that of the total gross annual theoretical benefit potential of eHealth in Australia, medication management is the greatest individual driver of benefits (\$3.2 billion or 39% of gross benefits).

These benefits are realised by the reduced incidence of adverse drug events, and thereby result in reduced patient harm and mortality in hospital settings and improved mortality and morbidity attributable to diseases that are sensitive to Quality Use of Medications, e.g. asthma, peptic ulcer disease, congestive cardiac failure, and schizophrenia.

The population benefits from de-identified sharing of adverse events with bodies such as the Therapeutic Goods Administration will have enormous benefits.

Currently there are multiple sources of medication lists available to the PCEHR with varying levels of clinical utility and functionality. From some sources there is an image of the current medication list, from some sources the current medication list is available as text, from some sources the information is coded and if the functionality existed would allow for import and export into and out of clinical systems as well as transmission by secure messaging from health care provider to health care provider.

In addition to that there is the National Prescribing and Dispensing Repository (NPDR). Each source is important in different parts of the patient journey. Ability to interact with the NPDR is variable at present and depends on whether the clinician's software interacts with it – General Practitioners, Pharmacist Public and Private Hospitals and Private Specialists.

The NPDR should be expanded to include a set of over the counter (OTC) medicines to improve its utility.

At present one of the subsidies that is available to the Pharmacist depends on whether the first script was dispensed electronically. To increase the rate of adoption this issue needs to be reviewed.

Over the counter medication is essential to detect such issues as poor compliance with Asthma treatment, to show up significant potential side effects with prescription only medicines and to allow for monitoring and support for drug dependent persons.

The two main data sources of data are complementary and neither can do the job of the other.

The curated current medications list together with adverse events, could be sourced from the GP, Specialist, Hospital or Aged Care Facility clinical information system, the discharge summary public or private is immediately clinically useful and will save time for the clinician on the receiving end.

It is imperative that further work be done on software systems to make the process of import and export and medication curation as seamless as possible to fit in to and streamline current workflow.

The NPDR when widely adopted will add another dimension allowing clinicians, particularly pharmacists, to track compliance and interactions with over the counter medication. It does not readily or rapidly allow clinicians to track a current medications list.



Recommendation

19. **Expand** the existing Australian Medications Terminologies (AMT) data set to include a set of over the counter (OTC) medicines.
20. **Widen** the existing National Prescribing and Dispensing Repository (NPDR) to include the expanded set of over the counter (OTC) medicines.

Discharge Summaries are widely accepted as an early driver of clinically relevant information that should form part of the minimum data set to facilitate the safe transfer of care into the community. Significant work has already been done in this area with the whole of QLD now able to upload discharge summaries to the PCEHR from all but two of its hospitals. The roll out is variable in other states with New South Wales uploading from all of its tertiary hospitals and will complete its rollout in 2015. South Australia metropolitan area is already live. Tasmania is expected to go live in 2014. The Northern Territory is already capable of uploading to the MyEHR. All of the other States need to come on board and their progress should be reported on by the Privacy and Security Committee.

The Australian Private Hospital CIO Forum through the submission from CHIK make the point that “the private hospital sector treats 40% of all patients in Australia, with private hospitals and day surgeries performing 2 out of every 3 elective surgeries in Australia. Private hospitals and day clinics provide more than 45% of chemotherapy treatments and admitted 4 out of every 10 patients who are aged over 65. Private hospitals treat more than 70% of people admitted for rehabilitation and perform 47% of heart surgeries. These cohorts of patients are expected to reap the most benefits from the sharing of their health information across the continuum of care.”

“Specialists are key stakeholders within the private healthcare sector as they refer patients into private or public facilities for admitted episodes of care and create discharge documentation for patients at the end of an episode of care.”

Quote - CHIK Services Submission

There is a need for early engagement with the private specialists and private hospitals to support and integrate with their existing workflows.

Work should proceed to allow the integration of diagnostic imaging and pathology into MyHR. According to the Pathology Australia submission there are 30 million pathology patient episodes per year involving over 100 million results. These would be a major contribution to the value of the MyHR to clinicians and patients.

Significant progress has been made by the NEHTA Clinical Useability Programme (CUP) to achieve access to pathology results. A similar process to the existing CUP process should be adopted by the clinical and technical advisory committee to deliver the solution.

The Royal Australian and New Zealand College of Radiologists make the following observations in their submission. There are significant barriers to use of the PCEHR by radiologists including the need to find, verify and incorporate Individual Health Identifiers (IHIs) in every Diagnostic Imaging patient



record, in addition to the range of identifiers already required by Medicare and other agencies and the lack of access to Secure Message Delivery (SMD) enabled software for access to the PCEHR, in both public hospital and private practice settings which need to be addressed. In addition there is no comprehensive standard list of 'orderable' Diagnostic Imaging examinations in Australia which will need to be developed.

The review advises that it recommends a change in the architecture of the eHealth Strategy to include the use of a decentralized information repository model, linked via MyHR. This may impact on the work that has currently already been done but will enable MyHR to provide access to existing private and publicly held repositories without the need for wholesale duplication of records.

The panel was fortunate to be able to visit the Northern Territory and see MyEHR in operation supporting predominantly the Aboriginal and Torres Strait Islander communities.

It is clear that the above functionality is a very useful clinical tool to the point where the Panel was informed that it would be impossible to effectively function without the full functionality that they already have including diagnostic imaging and pathology and clinical measurements. The importance of clinical measurements was very clear during our visit to the renal unit where the simple recording of dry weight can inform the clinician about the level of acuity of a renal patient presenting in any one of the nodes served by MyEHR.

In relation to clinical measurement the submission from the Aged Care Industry Information Technology Council noted that in addition to "Discharge/Transfer Functionality" and the "Medication Record" it would be important to "capture vital signs to prevent avoidable hospitalisation and demonstrate meaningful use of PCEHR."

Recommendation

21. **Implement** a minimum composite of records to allow transition to an opt-out model by a target date of 1st January 2015 inline with recommendation 13. This will dramatically improve the value proposition for clinicians to regularly turn to the MyHR, which must initially include:

- Demographics
- Current Medications and Adverse Events
- Discharge summaries
- Clinical Measurements

22. **Work** should proceed to allow the integration of diagnostic imaging and pathology into MyHR but their delivery dates should not delay transition to opt-out.

These items should be the primary focus of work. All other functionality of the PCEHR currently under development apart from Diagnostic Imaging and Pathology should be deprioritised while these data sets are configured.



Strengthening eHealth Technical and Data Foundations

Implementing an eHealth system requires a series of unified, integrated and extendable foundations that enable government and the private sector to provide secure and highly available software solutions to the health industry and patients.

Appropriate balance must be struck between those foundations that are provided by the public sector and those that are provided by the private sector, acknowledging significant investment is needed to build, operate and enhance the foundations necessary to support the ongoing reform of the Health sector.

Foundations include patient and doctor identifiers that are facilitated by digital identity and authentication solutions, open standards to ensure interoperability and exchange of information in a secure way, directory services that enable information to be found and connected and importantly, an open health record that exchanges information for the benefit of driving improved patient care outcomes and efficiency in the health industry.

For simplicity of definition, the Technical and Data foundations are identified as:

Health Identifier Service (HI Service)

National system for uniquely identifying healthcare providers (healthcare provider organisations and individual healthcare providers) and individuals.

National Authentication Service for Health (NASH)

Access control mechanism for the medical industry, based on Public Key Infrastructure (PKI) Certificates, that enables access to the Personally Controlled Electronic Health Record (eHealth record) system, and to send and receive messages securely using software that meets the requirements of Secure Message Delivery.

myGov

Access control mechanism for consumers, that enables identification and access to the Personally Controlled Electronic Health Record (eHealth record) system.

Personally Controlled Electronic Health Record (PCEHR)

An electronic summary of a patient's health records, that is available to facilitate information exchange between health providers and for patients to receive improved patient care. The information contained in a record is accessible to a patient, with several features enabling the patient to determine how information can be accessed and used by providers. This will include information such as medications, hospital Discharge Summaries, allergies and immunisations.

Secure Messaging

A communications system made up of multiple providers that enabling secure electronic transfer of information between clinical industry.



Provider Portal

Web-based platform enabling clinician access to eHealth records.

Consumer Portal

Web-based platform enabling consumer access to their eHealth records.

National Prescription Dispense Repository (NPDR)

System enabling population of Medication Dispense information to the PCEHR.

Healthcare Information and PCEHR Services (HIPS)

Integration software that facilitates integration of hospital and other systems with the PCEHR in an accelerated timeframe, enabling publishing of applicable health records sooner.

Data Standards

Policies and standards that define common structures for representing how data should be stored and/or exchanged between systems. These standards facilitate interoperability.

Messaging Standards

Policies, standards and design patterns that define how messages and information should be passed between systems. The standards facilitate open messaging systems and interoperability of messaging platforms.

Information Security Standards

Policies and standards that define common methods for the secure and trusted exchange of information, and ongoing management of that information.

Directory Services

An electronic service that enables storage, searching and access to information needed to facilitate interconnectivity within the eHealth system. Examples include National Healthcare Providers Directory (NHPD) and the National Healthcare Service Directory (NHSD).

It is acknowledged that other infrastructure foundations exist and enable interconnectivity e.g. B2B gateway, mobile gateways. These capabilities are seen as enabling capabilities for the Foundational Services above and for the purpose of this definition, are assumed to be included in the scope of defining foundational services.

In addition to the definition above, modern governments and systems also promote and accelerate the use of open data, as a system for sharing non-patient identifiable information with the government and private sector as a means for facilitating innovation in new products and or services that need to be introduced. Given Australia's future is linked with developing and enabling a strong digital economy, moving to become a leader in fostering innovation in health from a strong set of technical and data foundations should be a priority, however development of technical maturity in the industry is needed to take full advantage of this potential.



Review Findings

Whilst the review findings were critical of the usability of the end-to-end solution across the PCEHR, NASH, myGov, Clinical Information Systems (CIS) and other input systems, over whelming support was provided for several of the investments made to date in important systems like the Health Identifier (HI), and Secure Messaging as immediately valuable platforms.

Consequently, the review findings are best summarised by acknowledging that the investment made to date has provided several foundations of great value to the eHealth system, however their benefit has not been realized due to poor usability, inability to agree standards and inability to adopt standards in a timely manner.

The review finding for each foundation is identified below:

Health Identifier Service (HI Service)

Excellent foundational system. Widely recognized for its value in linking information between disparate systems. Further focus needed for widespread rollout of identifier service across all healthcare systems.

National Authentication Service for Health (NASH)

Large volume of feedback received that the system is complex, with multiple certificates required to submit information. Overall platform was implemented in an accelerated timeframe and compromises were made in the usability and implementation of the solution. Some correction and improvement made to the platform, but gaps remain. In addition, multiple platforms exist with the review noting implementations of NASH and NASH+, however the exact detail of current operating software and solutions would need to be validated. In addition, a review of the ongoing applicability of the architecture to support an opt-out model, together with reviewing the consolidation and simplification of potentially multiple NASH platforms, and the alignment of the National Authentication Service for Health with other government initiatives for digital identity and authentication, including the recommendation for developing a single-sign on capability, will be important to complete and to action any recommendations.

myGov

Feedback received that system is difficult for consumers to use and register for the PCEHR. Multiple steps and volume of information needed is significant and not often known to the patient when registering.

Personally Controlled Electronic Health Record (PCEHR)

A significant number of responses commented on the PCEHR itself, and how clinicians are able to interact with the PCEHR. Key findings:

- Insufficient information in patient records to provide clinical value.
- Insufficient volume of patients registered to have a PCEHR to provide clinical value.
- Input of information into the PCEHR does not integrate well into clinician's workflow, resulting in additional time needed to complete records e.g. Shared Health Summaries.
- The current user interface of the PCEHR results in it being viewed as a "dumping ground" for information, and it is difficult to find and locate information required. User interface



design against viewing Minimum Composite of Records, filtering of information to ensure instant access to relevant information without having to sift through record to find it.

Secure Messaging (SMD)

Secure Messaging was identified as an important enabler of interoperability between clinicians and to facilitate improved information sharing. The current industry has several providers, however support for adopting a common messaging standard to ensure messages can be communicated with anyone in the industry has not been forthcoming. A standard has been identified, however software providers have not adopted this strategy in a manner that enables true interoperability, resulting multiple proprietary networks and an inefficient outcome for users who must use multiple different products depending on who they need to interact with. A new approach is needed to ensure compliance with the standard, either through defined compliance programs that ensure providers meet the intent of the strategy and enable true interoperability linked with ensuring only compliant providers must be used to receive the ePractice Incentive Payment (ePIP), or via centralisation of messaging to operate through a standards compliant messaging gateway. This work would require evaluation, however immediate action is needed to ensure meaningful progress is made.

In addition, Secure Messaging is a closed network that operates between clinicians and it has not been designed to include providing Secure Messaging to patients and consumers. Action must be taken to expand the scope of Secure Messaging to a next generation service that ensures interaction between the medical profession and consumers for information that must be passed in a reliably secure manner to facilitate improved workflow and secure communication of private information.

Work must also be performed to review the usage of the ECLIPSE platform being used extensively in the hospital sector for similar messaging purposes (and more), with a view to identifying a method of integration and alignment of these important systems, and further extension of these platforms as needed.

Provider Portal

Provider Portal has good potential, but usability (see PCEHR findings) and ability to immediately access from CIS systems as part of standard workflow critical implementation priority. This portal should be accessible via a link or icon from within CIS or interfacing software that enables access to a record on MyHR that can be immediately accessed as part of standard workflow.

Consumer Portal

Consumer Portal important to providing patients with ability to understand who is accessing information and what information can be used. Controls included in the PCEHR are sound and empower patient consent with what information can and cannot be viewed by others.

National Prescription Dispense Repository (NPDR)

The NPDR is a key repository in the national eHealth infrastructure and will store medications information including prescription and dispensing data for consenting PCEHR registered patients. The contracted pharmacy vendors are Fred IT and Simple Retail, comprising approximately 62% of the market. So far only 49,282 documents are in the repository.



Healthcare Information and PCEHR Services (HIPS)

System developed by South Australia Health for integration of public systems and then reused in the Northern Territory and Queensland. Provides low cost method for integration of information, however needs support from national provider to manage upgrades and improvements as needed.

Data Standards

Alignment of Data Standards has been identified as a critical and ongoing need for enabling the interoperability of systems and also alignment of industry terms and language that will be used to populate Shared Health Summaries, Event Summaries and records posted to MyHR.

Multiple areas were identified in the review as needing standards work including the pathology and diagnostic imaging industry, standardisation of medication terminologies (also a separate recommendation in this review) and standardisation of care plan terminology.

Ongoing work must be performed by ACeH and its associated advisory committees to quickly move to agree standards and common terminology that is deemed a critical data foundation for the interoperability of MyHR.

Messaging Standards

SMD Standard in place for substantial time, however implementation has been delayed given waiting period for private software providers to consider adoption of the standard. Issue that adoption removes competitive advantage of closed networks that are in use.

Information Security Standards

Implementation of Information Security and Privacy standards and associated compliance is fragmented in the industry. Risk of information loss is significant from aged systems and needs to be reviewed in detail, with an appropriate plan for remediation developed.

Directory Services

Two directory services exist. Feedback received that need to consider consolidation of directory services given little perceived difference in the services.

In addition to the above, provision is needed to improve the availability and use of purpose designed training and education programs that accelerate usage, adoption and acceptance of the MyHR platform. This includes design of education programs in consultation with industry representatives and/or rollout of training in partnership with industry associations to take advantage of the value received from training by peers. (Recommendation 30)

In addition, access to an online training environment that is fully featured and aligned with the version of the MyHR platform in operation is needed to ensure users can access and improve knowledge and experience of using the system in a simulated and live environment.



Recommendations

In consideration of the findings and submissions to the review, the following is recommended:

23. **Implement** a standardised Secure Messaging platform for the medical industry, prioritising support for standards compliant platforms.
24. **Expand** the Secure Messaging strategy to include exchange of secure communication between the medical industry and consumers to facilitate improved communications and workflow efficiencies.

The intent is to enable a next generation of Secure Messaging capability that can enable instant and secure communication between the medical industry and consumers for the purpose of enabling workflow and communication of information that is appropriate to exchange electronically and without an in person discussion. This capability is in line with the Government's policy.

25. **Review** the NASH platform with a view to evolving the platform to align with the recommendations for Digital Identity that is included in the Coalition's Policy for E-Government and the Digital Economy.
26. **Review** the current development program for the PCEHR and deliver prioritised usability improvements based on user centred design principles in partnership with industry. The usability improvements to be designed to complement everyday workflows.

Includes redesign of the Health Summary record front page to enable easy access to (when available):

- current medications list - allergies and adverse events
- immunisations
- medical history
- hospital discharge
- pathology/radiology

Lean Six Sigma (LSS) methods and User Centered Design principles are modern approaches for optimising process efficiency and for designing software that provides user experiences that are tailored to meet the needs of users who interact with a given system.

The future design process for the MyHR, must adopt both methods as part of a new design philosophy, approach and continual improvement discipline that must drive enhancements in usability based on seeking user feedback, detailed analytics of user behaviour, and standards based design.

Review of the
Personally Controlled
Electronic Health
Record



27. **Add** a flag to the clinical author to identify if their patient has restricted or deleted a document in their MyHR to facilitate a discussion on the clinical impact
28. **Notify** the consumer via an SMS message when their MyHR is opened or used by default. For patients that do not have a mobile number, a message will not be sent, however mobile contact number should be requested as part of the standard information for a customer's profile.
29. **Enable** a single sign-on capability that enables simplified usability as users of the systems are able to seamlessly pass from one system to another.
30. **Evolve** education, training and implementation programs to engage industry associations in the design and delivery of programs. This includes implementation of online training tools, including provision of a simulated MyHR environment to support required training volumes.



Creating an eHealth Ecosystem

Open, collaborative approaches between the government and private sector, where innovation is encouraged, invested in and rewarded, has progressively driven advances in many industries and economies.

The Health Care Industry is a fragmented industry when compared to other industries. This results amongst other things, in inefficiencies for medical providers operating their businesses in this environment, and frustrating experiences for patients looking to receive care across multiple providers.

The creation of a successful eHealth ecosystem, refers to developing appropriate approaches to introduce solutions to the industry that acknowledge the fragmentation of the industry, specialisation of private organisations, and the industry policy settings and strategies needed to be deployed by governments to encourage continuing investment and evolution of the industry.

This may include the decentralisation of decision making and empowerment to enable smaller, workable health care communities to deliver solutions that can then be proven and scaled quickly to benefit larger communities. It can also include recognising private sector investments in enabling technologies and how these technologies could form part of connected network of services that deliver patient outcomes. The latter would require the right mix of regulation, standards, frameworks, and open communication to ensure that both public and private sector needs and benefits can be achieved.

Review Findings

The review has heard from multiple medical industry associations and software providers. A strong theme of constraints being imposed on the industry due to the centralist approach taken with the PCEHR, has been shared.

A perceived centralist approach, led by NEHTA and the Federal Department of Health has been identified as reducing confidence of the private sector to invest in product development and evolution, reducing the willingness to collaborate given multiple comments that information was often shared with NEHTA with little received in return.

In addition, the PCEHR is perceived as wanting to build a single data repository to satisfy the requirements of the entire industry. Whilst our review has found this claim to be inconclusive, concern does exist from multiple industry organisations that the value that can be achieved by enabling an interconnected set of data repositories is being overlooked and work is needed to review the potential benefits for accelerating a number of benefits for the healthcare industry and patient community.

Examples of important and critical repositories of data are in the Pathology and Diagnostic Imaging industry, where private sector investment and innovation has developed system that enable storage, sharing and viewing of tests and/or records. These systems should adopt the Healthcare Identifier Service (HI) for stored information and be extended to integrate with a centrally provided single-sign on service that simplifies usability and improved adoption into clinical workflows.



Recommendations

In consideration of the findings and submissions to the review, the following is recommended:

31. **Immediately** update the MyHR strategy to actively enable decentralisation of information across multiple data repositories, with information being linked using the Healthcare Identifier (HI).

The MyHR be updated to act not only as a data repository, but also an information exchange and providing important linkages to third party data repositories and information where it is stored.

32. **Reset** the policy standards and frameworks necessary to enable interoperability, in a decentralised model, plus commercial models that ensure providers can generate an acceptable return on the investments made in shared infrastructure.

33. **Prepare** a business case that defines appropriate methods of compensation for investment should be investigated that include one-off costs and/or transaction fee services for clinical access to records associated with integration of existing data sets into the MyHR.



Introduce Enabling Measures and Incentives

Metrics and incentives are an important and integral part of a system of health care. Selecting the right metrics and incentives is critical for supporting the introduction, perceived momentum, trust and value that both patients and the clinical community realize from this important investment.

Future metrics for the MyHR should provide transparency in actual performance and be constructed in a manner that aligns with the real experiences being felt by patients and the medical industry. This is a critical step for building trust and continuing the commitment to transition to the widespread use of the eHealth system. Metrics must also be used to showcase results that can be achieved, provide recognition for leaders in the industry who are driving change, and identify where performance is unacceptable and requires improvement.

Future incentives for the MyHR should be used in a manner that motivates the multiple parties involved in the delivery of eHealth services to deliver improved productivity, efficiency and patient care outcomes. Incentives can be in the form of cash, access to services and/or rewards that are provided. They can be and/or should be temporary in nature and used to motivate process and/or behavioural change in accelerated timeframes.

The implementation of an eHealth system requires the industry to collaborate, exchange information and share in an increasingly efficient way. Issues of intellectual property, privacy of information, agreeing on standards all require compromise from the varied parties in the industry and continuing commitment is needed to find common ground in order to accelerate the benefits that can be achieved for patient care.

Review Findings

The introduction of the PCEHR was driven by the need for the Health Industry to continue a process of reform to drive efficiencies into the health care system, improve the quality of patient care, whilst reducing several issues that were apparent from the lack of important information that is shared about patients e.g. reducing the rate of hospital admissions due to issues with prescribed medications. This reform is critical to address the escalating costs of healthcare that become unsustainable in the medium to long term.

The business case identified that the PCEHR would benefit several key areas:

- Efficiency of the healthcare system by:
 - Removing wasted time in collecting and finding information
 - Removing duplicated or unnecessary treatment activity
 - Reducing pressure on the healthcare workforce
 - Better coordinate healthcare across distributed boundaries and jurisdictions
- Quality of care provided in the healthcare system
 - Improving patient safety
 - Reducing frustration of patients repeating information
 - Removing reliance on patient memory



- Implement a national system that aimed to remove waste from investment in competing platforms and systems
- Providing equity in the healthcare system for providers

The findings to date have identified continued commitment to these goals, and ongoing frustration they are not being achieved, and in the context of metrics and incentives, the Panel has not identified a unified method of metrics and incentive alignment that is working to achieve the goals of the PCEHR.

The current approach to measurement appears to respond to current issues in the PCEHR that are driven by wanting to limit the frustration and poor perception issues of the PCEHR, whilst also providing an ability to enable adoption. As a result, metrics report on the number of registered users, and the information that is being added to the record.

The current approach does not appear to communicate how the overall benefits of this investment are being realised, recognition for achievements of individuals or communities that make positive contributions to benefit outcomes and when the expected efficiencies and patient benefits are being realised.

Types of Incentives

Incentives have been used in the healthcare industry over time. Incentive models range from annualized payments when defined criteria are met, to payments based on a per transaction model as well as point in time payments to encourage practitioners to embed a process (e.g. Video consultation) into normal practice. An example of incentives are:

- ePractice Incentive Payment (ePIP)
Incentive payment to GP's to incent investment in eHealth foundations for their practices.
- Meaningful Use Incentives
Incentive payments issued as one off or transaction payments that are paid on achievement of meaningful outcomes for the clinical industry and/or patient care.
- ePrescription Incentive
Transaction based incentive to incent industry to invest in solutions that drive electronic prescription exchange between providers.
- Telehealth incentive payments
The first is paid after the first Telehealth MBS claim and the second after the tenth
- Transaction payments for specific outcomes such as Care Plans.

The Panel has found that criticism is levelled at all types of incentives, either driven by views that they manipulate the free market, or are not as inclusive as is needed. The overwhelming majority of view is that ongoing incentives are needed to enable continued investment in building a sustainable ecosystem of healthcare providers and services and one that also enables and rewards innovation that is driven in the industry. More detail on applicable incentives is below.

Practice Incentives Program – eHealth Incentive (ePIP)

The ePIP eHealth Incentive aims to encourage general practices to keep up to date with the latest developments in eHealth and adopt new eHealth technology as it becomes available. It aims to help practices improve administration processes and patient care. Eligible practices can receive a maximum payment of \$12,500 per quarter.



To be eligible for the ePIP eHealth Incentive, practices must meet each of the five requirements which prepare the practice for interaction with the PCEHR, Secure Messaging and Electronic Transfer of Prescriptions by ensuring the practice is using complying software.

The requirements are as follows;

- Integrating Healthcare Identifiers into Electronic Practice Records
- Secure Messaging Capability – the practice must have the ability to transmit and receive
- Data Records and Clinical Coding – the practice is working towards the majority of diagnoses for active patients to be coded.
- Electronic Transfer of Prescriptions – the practice must sent the majority of prescriptions electronically.
- Personally Controlled Electronic Health (eHealth) Record System – the practice must use compliant software for accessing the personally controlled electronic health (eHealth) record system.

Over time the Practice Incentives Program has gradually lifted the bar to first prepare a practice for activity and then incentivise that activity. The panel supports this process.

Meaningful Use Incentives

Meaningful use incentives are an impactful method of using metrics and are used in the healthcare industry both domestically and internationally to align and unite the multiple parties that need to contribute to the delivery of benefits across the healthcare system. A good example is the PIP Diabetes incentive. This payment is aimed at supporting general practice activities that encourage continuing improvements and quality care, enhance capacity and improve access and health outcomes for patients.

Care Plans, Health Assessments and Medication Management Reviews

A care plan refers to a specific service provided by a GP or particular specialists to allow more comprehensive treatment of certain medical conditions.

A patient who has a chronic or terminal medical condition (with or without multidisciplinary care needs) can have a GP Management Plan (GPMP) service which sets out a structured approach to their care and may be followed up by a Team Care Arrangement (TCA) to enables a GP to plan and coordinate the care of a patient with complex conditions requiring care from a multidisciplinary team.

For example, a child with autism may receive a care plan from a paediatrician or psychiatrist under the Helping Children with Autism Program.

A child with certain conditions may receive a care plan from a GP, Specialist or Consultant Physician under the Better Start for Children with Disability Initiative.

There are also health assessments able to be provided by a medical practitioner targeted at children, persons aged 45-49 at risk of a chronic disease, and persons aged 45-49 at risk of diabetes, aged 75



or older, permanent residents of aged care facilities, persons with an intellectual disability and for refugees and other humanitarian entrants.

A domiciliary (patient living at home) or residential (patient living in a Residential Aged Care Facility) Medication Management Review is intended to maximise an individual patient's benefit from their medication regimen, and prevent medication-related problems through a team approach, involving the patient's GP and a pharmacist.

Medication Management Reviews are targeted at patients for whom quality use of medicines may be an issue or who are at risk of medication misadventure because of factors such as their co-morbidities, age or social circumstances, the characteristics of their medicines, the complexity of their medication treatment regimen, or a lack of knowledge and skills to use medicines to their best effect.

Risk factors known to predispose people to medication related adverse events are:

- Currently taking five or more regular medications.
- Taking more than 12 doses of medication per day.
- Significant changes made to medication treatment regimen in the last three months.
- Medication with a narrow therapeutic index or medications requiring therapeutic monitoring.
- Symptoms suggestive of an adverse drug reaction.
- Sub-optimal response to treatment with medicines.
- Suspected non-compliance or inability to manage medication related therapeutic devices.
- Patients having difficulty managing their own medicines because of literacy or language difficulties, dexterity problems or impaired sight, confusion/dementia or other cognitive difficulties.
- Patients attending a number of different doctors, both general practitioners and specialists; and
- recent discharge from a facility / hospital (in the last four weeks).

All of the above services items target those Australians that are most likely to gain benefit from having up to date health information on their MyHR and it is the panels view that when these services are delivered it would be a great opportunity to add significant clinical value for a high needs subset of patients. With that view in mind it should be a requirement when delivering these services that a copy of their written plan be uploaded to their MyHR.



Recommendations

In consideration of the findings and submissions to the review, the following is recommended :

34. **Introduce** by ACeH Board a new balanced scorecard of metrics that includes primary metrics (e.g. meaningful use metrics) and secondary metrics (e.g. leading indicators) that are aligned with the benefits and goals of the MyHR.

The ACeH board will be responsible for governing and determining the balanced scorecard that will be used across each advisory committee.

35. **Apply** governance principles of transparency of metrics and reporting to build confidence in the clinical relevance of information that is provided.
36. **Change** the ePractice Incentive Payment (ePIP) to introduce meaningful use metrics that incent contribution of clinical relevant information to the MyHR, including linking ongoing ePIP funding to actual usage of the MyHR.
37. **Commission** a scoping project to identify the options available to encourage further take up of electronic transmission of data by specialist medical and allied health professional practices and private hospitals.
38. **Alter** the Medicare Item number requirements from January 1st 2015, for health assessments comprehensive assessments, mental health care plans, medication management reviews and chronic disease planning items to require a copy of the information to be uploaded to the MyHR.



Addendum 1 Organisations who made Written Submission

Aboriginal Health Council of South Australia (AHCSA)
Aboriginal Health Council of Western Australia
Aged Care Industry Information Technology Council
ACIITC
ACSA
Aged Care IT Vendors Association (ACIVA)
Allied Health Professions Australia (AHPA)
Association of Independent Retirees (A.I.R.) Limited.
Australian Association of Consultant Physicians (AAPC)
Australian Association of Pathology Practices
Australian Association of Practice Managers
Australian College of Nursing
Australian College of Rural and Remote Medicine
(ACRRM)
Australian Dental Association Inc (ADA)
Australian Diagnostic Imaging Association
Australian E-Health Research Centre CSIRO
Australian Federation of AIDS Organisations (AFAO)
Australian Health Insurance Industry Association
Australian Information Industry Association (AIIA)
Australian Medical Association (AMA)
Australian Medicare Local Alliance
Australian Nursing and Midwife Federation (ANMF)
Australian Osteopathic Association (AOA)
Australian Physiotherapy Association (APA)
Australian Primary Health Care Nurses Association
(APNA)
Australian Privacy Foundation (APF)
Australian Private Hospitals
Australian Psychological Society APS
Avant Mutual Group
Best Practice GP Software
CanSpeak The Voice of Cancer Community Australia
Catholic Health Australia
Consumer e-health Alliance
Consumers Health Forum of Australia
Department of Communications
Department of Veterans Affairs (DVA)
Dietitians Association of Australia (DAA)
Dr. David G More
Focus Health Network
Fred IT Group
General Practice SA
General Practice Victoria
Health Informatics Society of Australia
Improvement Foundation
Victoria Healthcare Association
Independent Information System Consultant
Lasa
Liberty Victoria
Macquarie Health Corporation
MDA National
Medical Software Industry Association (MSIA)
Menzies School of Health Research
Metro North Brisbane Medicare Local
National Aboriginal Community Controlled Health
Organisation (NACCHO)
National Coalition of Public Pathology (NCOPP)
National E-Health Transition Authority (NEHTA)
National Prescribing Service
National Rural Health Alliance (NRHA)
NSW Council for Intellectual Disability
Office of the Australian Information Commissioner
Optometrists Association Australia
Organisation
Palliative Care Australia (PCA)
Positive Life
Primary Health Care Limited
Primary Health Care Limited
Private Health Care Australia
Queensland Department of Health
Queensland Nurses' Union
RMIT University
Royal Australian and New Zealand College of
Radiologists (RANZCR)
Royal College of Pathologists Australasia
Rural Doctors Association of Australia (RDAA)
South Eastern Melbourne Medicare Local
Standards Australia
Symbion
Tasmanian Government - Department of Health
Telstra
The Australasian College of Health Informatics (ACHI)
The Medical Insurance Group (MIGA)
The Pharmacy Guild of Australia
The Royal Australasian College of Physicians (RACP)
The Royal Australian College of General Practitioners
The Society of Hospital Pharmacists of Australia
Townsville- Mackay Medicare Local
University of New South Wales
Victoria Healthcare Association
Western Sydney Medicare Local WSML



Addendum 2 Personal Controls Matrix

ATTACHMENT A PCEHR – Overview of Document Types, Access Controls and Role Permissions		This overview table summarises the system document types, access controls for who may view or add various documents, and individual/ representative permissions to perform various system functions.						
A. DOCUMENTS		Document Type				Document Access Level		
		Consumer		Medicare Admin (note 3)	Clinical (note 4)	'General' Access Document (note 5)	'Restricted' Access Document (note 6)	
		Consumer-Only (note 1)	Consumer-Shared (note 2)					
Documents								
Personal Health Notes		✓				✓	✓	
Child Development - Achievement Diary		✓				✓	✓	
Personal Health Summary - Medications, Allergies & Adverse Reactions			✓			✓	See note 7	
Child Development - Personal Observations, Child Parent Questionnaire			✓			✓	See note 7	
Advance Care Directive Custodian			✓			✓	See note 7	
Emergency Contacts			✓			✓	See note 7	
Medicare Information (MBS, PBS, ACIR, AODR)				✓		✓	✓	
Shared Health Summary					✓	✓	See note 7	
Event Summary					✓	✓	✓	
Discharge Summary					✓	✓	✓	
eReferral					✓	✓	✓	
Specialist Letter					✓	✓	✓	
Prescription					✓	✓	✓	
Dispense					✓	✓	✓	
B. ACCESS CONTROLS						'General' Access Document	'Restricted' Access Document	
Access Controls								
PAL - Provider Access List. Read Access or Write Access, for General or Restricted documents - see note 8						✓	✓ (note 8)	
PAC – Personal Access Code (Given to & used by Nominated Representatives - see note 10)						✓	✓ (note 10)	
RAC – Record Access Code (Given to & used by Providers/Organisations) - see notes 11,13						✓	✓ (note 11)	
LDAC – Limited Document Access Code (Given to & used by Providers/Organisations) - see notes 12,13						✓	✓ (note 12)	
C. ROLE PERMISSIONS		Roles						
System Functions (via Consumer & Provider Portals)		Individual Consumer	Authorised Rep	Nominated Rep- General access	Nominated Rep - Restricted access	Full Access Nominated Rep	Provider	
View 'General' documents		✓	✓	✓	✓	✓	✓	
View 'Restricted' documents		✓	✓		✓	✓	✓ (note 6)	
Author Consumer documents		✓	✓			✓		
Remove documents - see note 14		✓	✓			✓	✓ (note 14)	
Change Document Access Level - General / Restricted		✓	✓			✓		
Set RAC / LDAC - for Providers/Organisations		✓	✓			✓		
Cancel record		✓	✓					
Change Provider Access Level - General / Restricted		✓	✓			✓		
Revoke or Remove Provider Access - see note 8		✓	✓			✓		
View Access History (Audit Log)		✓	✓			✓		
View Authorised Reps		✓	✓			✓		
View Nominated Reps		✓	✓					
Add Nominated Reps		✓	✓					
Manage Notification Settings (email, SMS to mobile phone, none) when the eHealth Record is accessed. Eg access by a new healthcare provider organisation, access in a medical emergency, access by a Nominated Representative.		✓	✓			✓		
Set Medicare Information Preferences (MBS, PBS, ACIR and/or AODR)		✓	✓					
Notes								
A. Documents		B. Access Controls						
<ol style="list-style-type: none"> Consumer-Only documents are NOT viewable by providers. Consumer-Shared documents ARE viewable by providers, depending on access permission. Medicare documents are collected by the Dept of Human Services (DHS) and/or the Dept of Veterans' Affairs (DVA), and may include MBS, PBS, ACIR and/or AODR records. Clinical documents contain information about your health written and added by your healthcare providers. General Documents: Any healthcare provider and all representatives who can access your record may access these documents. This is the default access - consent given during registration. Restricted Documents: A consumer can set specific documents to 'Restricted' access. Only healthcare providers (a) with a Limited Document Access Code (LDAC) or (b) on the Provider Access List with 'Restricted Access' can view/upload these documents. Authorised Representatives and Full Access Nominated Representatives may also view Restricted documents. These documents cannot be Restricted. All providers with access to the eHealth record will always be able to view these documents. 		<ol style="list-style-type: none"> Provider Access List (PAL) - When a provider accesses the eHealth record for the first time, the organisation they represent is added to the PAL. On the PAL, both Read and Write (upload) settings allow access to Read and Write 'General' and/or 'Restricted' documents. Provider organisations on the PAL may have their Read access Revoked (blocked) by the consumer. Consumers may also Remove an organisation from the PAL which effectively reinstates access to General documents unless a RAC is in place. Note Providers may upload documents even if [Read] access is set as Revoked. Emergency Access by providers overrides all access controls, ie view of both 'General' and 'Restricted' documents for 5 days. Personal Access Code (PAC) - a code to allow Nominated Representatives access to the eHealth record. Record Access Code (RAC) - a code set by the individual/consumer and given to providers/organisations to enable access to the eHealth Record ('General' documents only). Limited Document Access Code (LDAC) - a code set by the individual/consumer and given to healthcare providers/organisations to enable access to 'Restricted' documents within the eHealth Record. RAC & LDAC codes - once entered by a provider, the record is available to all healthcare providers within the same healthcare organisation. As a document author, a healthcare provider who uploads a document will always be able to see and remove the document they created regardless of the access settings applied to the document. 						



Addendum 3 Key Themes from stakeholder feedback in detail

The central benefits of the PCEHR are a reduction in avoidable hospital admissions and GP visits due to more effective medication management and improved continuity of care across the health sector by providing healthcare providers with access to clinical documents, such as an electronic Discharge Summary.

Quote APH (CHIK)

The lack of a detailed business case (or even a simple one), the lack of infrastructure implementation oversight, the lack of adequate governance and community oversight more broadly, and the lack of an implementation plan have all led to where we are today, reviewing a (reportedly) "shambolic" system.

Quote CeHA

1. Personal / Patient Control

The PCEHR like any healthcare technology may do good or harm. Correct information at a crucial moment may improve care. Misleading, missing or incorrect information may lead to mistakes and harm. There is clear evidence nationally and internationally that health IT can cause such harm.

Quote – Professor Enrico Coiera, Director Centre for Health Informatics, Australian Institute of Health Innovation, UNSW

Contrary to patient/consumer expectations of personal control, clinicians and others will mediate each patient/consumer interaction with the PCEHR.

Quote - Liberty Victoria

Many responses debated the merits of a system that provides the option for the patient to choose which data will be uploaded to the system, believing that this creates an incomplete picture of the patient's medical history and compromises the ability of the health care practitioner to make informed clinical decisions for their patient.

Arguments were put that personal control would appear to be in direct conflict with the objective of improved access to key clinical information across healthcare settings for the good of the health system.

It was felt that personal control leads to the potential for inaccurate or incomplete data and that means that the PCEHR cannot be relied on as a trusted source of key clinical information.

Clinicians need to be confident that if the PCEHR, offers additional information to assist them in their care of their patients, it will be complete and available to them.



A number of submissions argued that in its current format the PCEHR doesn't assist or enhance the medical practitioner's role in: providing healthcare; and managing the care of their patients with other healthcare practitioners, beyond their own skills and experience and using the tools they already have available.

It was suggested that the clinical utility of the PCEHR could be significantly improved if patient control was exempted for key elements such as medications, adverse events, discharge summaries, recent results of diagnostics tests, and shared health summaries.

The ability for patients to block access to, or remove, certain parts of their record should be reconsidered.

Other submission's argued that Personal Control remained at the core of the systems acceptance by consumers and that the consumer must retain the ultimate rights over what goes into their records and who can remove, access and change information therein.

- The record cannot be described as personally controlled if a population group (e.g. Aboriginal and Torres Strait Islander peoples) do not have the skills or tools to personally control it.
- PCEHR will not be a complete record ... because patients can delete or block access ...
- As currently designed, the control by patients as to the type of information that can be shared with clinicians fails to recognise the risk this creates to patient safety.
- At present, the PCEHR is too focussed on the general concerns of patients and insufficiently considers the specific needs of practitioners recording information.
- Patients should not have the right to delete relevant and accurate health information unless there is a system of mandatory annotations whereby the PCEHR is annotated to denote the existence of a deletion.
- The ability of patients to limit health practitioner access to their eHealth record or to particular documents within the record may impact on patient safety and limits the clinical usefulness of the record.
- There is significant concern about the high level of consumer control.
- The PCEHR would be a valuable clinical tool if the personally controlled element was removed.

Placing control of the data in the hands of the patient in an effort to empower them regarding their clinical care is a noble aim, however it is fraught with issues as the patient has the right to not include vital clinical and laboratory data that is essential for ongoing interpretation and monitoring of care.

Quote RCPA



Sweden - The Patient Data Act, passed in 2008, permits citizens to have the right to electronic access their own health information, they do not have the element of personal control that is evident in the Australian model.

Quote MDA National

2. Opt-in opt-out

Opt-in

The current registration process, including assisted registration, is often referred to as clunky and over complicated. With the vast majority of patients currently without a PCEHR, medical practitioners generally lack any incentive to adopt the system. For practices, the impost on practice staff time, in assisting to register new users is significant and some practices are unwilling to introduce this additional service as a result. Without a clear understanding of the potential benefits there is limited motivation for both consumers and health practitioners to sign-up to the system. There is evidence of strong support for reconsidering this opt-in model by those who provided feedback.

Opt-out

Costs associated with patient registration and the related debate around providing financial incentives to the health care industry to assist, are likely to be eliminated with the introduction of an opt-out model. An opt-out model would also help create the critical mass required to incentivise medical practitioners to commit to using the PCEHR, as they would no longer need to be concerned about whether or not a patient record existed. It would help to remove a significant barrier to patient participation and generally improve PCEHR adoption rates. For vendors, achieving a critical mass of users would help drive innovation.

Specific user groups that could potentially see significant benefits from a PCEHR, such as the disadvantaged and those living in rural and remote communities, are currently amongst those who are least likely or able to register. An opt-out model would help resolve the difficult registration process and enable them to realise the benefits of a PCEHR.

“As proven in the telecommunications industry with innovations such as texting and photo messaging, the value of a networked system increases with the number of people using it”

Quote NEHTA

- An opt-out model in which all consumers are allocated a record would increase the likelihood of participation in the PCEHR and full benefits could be realised.
- A change to an opt-out model would also allow a refocusing of activity from consumer registration to actually supporting the clinical usage of the PCEHR.
- The current ‘opt-in’ approach has created more work for health professionals in the start-up phase. With few perceived incentives to undertake this work, and with competing workload priorities, the level of use of the PCEHR by health professionals in clinical settings has not been as high as expected



- If a citizen's PCEHR was accruing information from the time of the systems inception until such time as they opted in, this would better meet both their expectations and those of their providers. It would also create a record that was immediately useful to the viewing clinician and patient leading to increased ongoing usage.

3. Barriers

There are a large number of perceived barriers that are impacting on the adoption of the PCEHR, some the issues highlighted include:

- The lack of perceived clinical usefulness.
- Poor integration with existing workflows.
- An overly complex and time-consuming registration processes.
- Concern about data security and integrity.
- The high costs of implementation and on-going development.
- Poor internet connectivity particularly in regional areas.
- The absence of compatible software, specifically in the specialist and allied health sectors.
- Poor computerisation in some sectors and a lack of incentive to invest in basic infrastructure.
- Complications associated with "team based care" and multiple transaction environments.
- Lack of easy to use and useful IT solutions/applications that connect to the PCEHR and which drive value for clinicians and patients.
- The lack of visibility as to whether data has been restricted or not, results in a lack of confidence in the PCEHR.
- Currently not supported in the terminal server environment.
- Lack of a business case, a case needs to be made for the business to invest in adopting change.
- In order to avoid the need for making multiple records, a system that easily connects with the existing records management systems in all jurisdictions should be a priority.
- The PCEHR system does not replace practice records but adds another layer of information, creating opportunities for error and fragmentation because clinicians are required to update/maintain the PCEHR in addition to their own practice systems.
- It does not provide tailored views of information so that diagnostically valid data may be lost in the plethora of other, irrelevant information.
- The healthcare system is drowning in information, much of which is unnecessary, for current patient care.
- the PCEHR system simply adds to this ocean of information without addressing the patient/consumer care concerns embodied in it
- A slow flow of discharge summaries from hospitals - including metropolitan, regional and small rural hospitals - would be a significant barrier to the usefulness of the PCEHR for rural and remote clinicians and their patients.
- At present there are no systems in place for palliative care patients to link their Hospital Identifier, and Palliative Care Identification Number with Health Care Identifiers.
- Discharge Summaries are currently limited to discharging an individual from hospital to the care of a GP. Discharge summaries will need to be broadened to include other palliative care service providers given the wide range of providers in palliative care and the settings in which palliative care is provided.



- Radiologist Barrier - The need to find, verify and incorporate Individual Health Identifiers (IHIs) in every Diagnostic Imaging patient record, in addition to the range of identifiers already required by Medicare and other agencies.
- It was not anticipated that the resultant registration processes would become so onerous and complicated, and the promise of a sophisticated National Authentication Service for Health (NASH) resulted in a complex array of digital certificates being required, each with its own disconnected registration process, technical issues related to installation and expiry, and ambiguous technical support pathways to address these.
- Clinicians and Medicare Local support staff, were under the impression that providers who did not use GP type clinical information systems would be able to contribute documents including event summaries through the online Provider Portal. There was much disappointment and disengagement, particularly by allied health providers, when, shortly after the appointment of the National Infrastructure Partner (NIP), they were told that there would be no write access to the Provider Portal.
- Key clinical documents still cannot be sent to the record, including:
 - Discharge summaries - from many public and private hospital services who did not participate in NeHTA/DoHA eHealth Site projects
 - Specialist letters from many public hospital clinics
 - Specialist letters from many private clinics due to the complex registration process or the absence of conformant software
 - Event summaries from many state funded services including public hospitals, allied health, community health, maternal and child health, and post-acute services
 - Event summaries from many private allied health providers due to the complex registration process or the absence of conformant software
 - Pathology & radiology results etc.
 - The absence of electronic care planning capability in the system
- Another key barrier is the cumbersome, complex, repetitive and onerous registration process for individuals, or practices, to participate. This process is very resource intensive and not an easy path for a provider (or their staff) to navigate without significant support.
- The level of support and advice provided by the various Medicare, Department of Health, and NEHTA helplines is widely reported/experienced to be varied and often conflicting.
- Even through the Assisted Registration channel, it can be very difficult for patients to gain access to their own record. This whole process needs to be simplified and streamlined.
- Multiple users with the same email address cannot register for a mygov.au account preventing them from accessing their record.
- Current views are difficult to read and contain information that needs to be filtered in order to view the detail that is required.

4. Secure Message Delivery

Clinicians need to be supported with infrastructure that encourages point-to-point communications between providers through universally available and interoperable secure message delivery. Once a culture of point-to-point communication is ubiquitous in clinical practice, the data captured through this process will be the foundation of a PCEHR, which is a point-to-share technology.

- It is a small step to progress from the point-to-point communication (directly between two clinicians) to the point-to-share (from clinician to PCEHR).



- The SMD interoperability needs to be expanded to cover all clinical information and management software. This will enhance interaction between providers and GPs and once this occurs additional upload to PCEHR becomes practical and logical.
- There is value for secure messaging and sharing of information between health practitioners for the benefit of patient care, however, for this to be adopted it needs to work more efficiently and effectively. The design of the system is predominantly from the perspective of hospital and medical systems rather than giving consideration to the predominant model in primary care of office based practice.
- The standards and services required for interoperable SMD have been finalised and delivered. However in the absence of an industry-wide commercial interchange model (as per the telecommunications and banking industries) there have been no cross-vendor transactions. This has fundamentally affected its universal use.

5. Consultation / Buy In / Engagement

Successful national health IT system must be orientated to supporting and improving patient care. If the PCEHR is perceived as an administrative system, rather than technological reform delivering better patient outcomes, there will be limited enthusiasm on the behalf of health care providers.

Quote VHA

It is acknowledged that a substantial amount of input was provided by various industry user groups during the development phase, and not incorporated into the PCEHR. Greater implementation of the recommendations provided during the development phase may have resulted in better acceptance and increased uptake of the PCEHR by both clinicians and individuals. Clearly, if the system is not designed around the realities of the clinical environment and workflows, then the uptake of the system will be limited.

- However - Great care needs to be taken that the eHealth initiatives and systems being implemented don't just automate current processes which do not provide best practice clinical care and business outcomes.
- The lack of engagement with industry in change management has resulted in industry being unaware of changes to the system that potentially impact their products, increases cost and risk.
- Consultation with regard to the PCEHR, through bodies such as NEHTA's Clinical Leads, should broaden in scope and representation to include allied health, including pharmacy.
- If the alignment of both clinical and business drivers for the adoption of the PCEHR can be achieved then the 'sell' of the system to health care business will be much easier.
- The administrative processes associated with the PCEHR are 'clunky' and overly bureaucratic, the process of accessing information from the record for clinicians can be time consuming, difficult and disruptive to their normal workflows and very little account was taken of issue relating to managing the data in practices that is needed to populate the PCEHR.
- More consideration of the role of consultant specialists, nurses, Aboriginal and Torres Strait Islander peoples, health workers and allied health professionals in their use of electronic records is needed.



- General practice nurses are potentially significant enablers in the implementation of the record, by providing the opportunity to align eHealth literacy and uptake by consumers and clinicians where eHealth will be of most benefit to the wider consumer community, and will ultimately drive safety and quality across primary and tertiary health care delivery nationally. Some of these opportunities are through:
 - Educating the consumer resulting in increased understanding of the benefits for the consumer, and demystifying eHealth for consumers.
 - Assisting consumer registration Cleansing and uploading data to shared health records.
 - Care coordination and care planning consultations for the chronically ill.
 - Captured time with parents during immunisation consultations.
 - Opportunistic consultations offering preventative health advice to younger or at-risk populations.
- Increasing participation by key cohorts will drive content creation which has been identified as a key enabler by clinical users, and is the critical next step to drive uptake of the PCEHR to reach a 'tipping point' of use. This involves completing the current workplan to include pathology and diagnostic imaging in the PCEHR, then expanding its use to include allied health professionals and specialists. Consumer registrations must also increase significantly to translate the work to date into beneficial clinical outcomes.
- all medical specialties, other than General Practice, have been largely ignored
- Make greater use of one-on-one consultation processes that protect the confidentiality with non-disclosure agreements. These processes are more likely to yield deeper insights into the PCEHR and potential solutions.
- Engagement should be underpinned by sound governance arrangements to ensure all key stakeholders in the private sector are able to influence the development of national eHealth initiatives in a manner that will support their operational processes and their current capability.
- extensive consultation initially conducted by NEHTA, however once the National Change and Adoption Partner (NCAP) was appointed, consultation was fragmented, and the feedback provided did not sufficiently feed through into the PCEHR design to deliver the desired functionality.

6. Performance Measures

PCEHR needs to change its 'measurement of success' focus from participation rates to 'clinical value'. A key measure of the success or otherwise of the PCEHR program has been based on patient registration. The number of PCEHR ready practices with IT systems in place and staff educated on, and familiar with, the PCEHR, may provide a better picture of the real rates of adoption.

A 'profession-by-profession eHealth scorecard' could be implemented to provide a mechanism to measure eHealth performance across the key professions. The implementation of such a system, developed with stakeholder consultation, will allow key stakeholders and peak NGO's to address any under-performance areas within their respective professions. It will also provide an 'identifier' for government for what is working well and which professions are performing and responding to government-led eHealth initiatives.

Many 'bells and whistles' being added without cementing down the basic usability of the front end PCEHR.



Participation numbers are politically driven.

7. Direction / Purpose / Value

Clinicians advise that the overwhelming priority for clinical staff is access to existing core documents such as referrals, discharge summaries and specialist letters and to communicate these across organisational boundaries. These are primary documents in most acute and primary care settings, frequently used and immediately relevant to current and future patient management. To the extent that these are not available, the value of the PCEHR is limited. Similar to clinicians, patients need easy to access and use registration processes, health record content that is meaningful to the current management of their health. If information is not flowing electronically today between the patients' healthcare providers then it's a stretch to implement this for the PCEHR.

Patient care meaningfully supported by electronic clinical documents, should include:

- Referrals and specialist letter (including versions for telehealth purposes)
 - Hospital discharge summaries
 - Aged Care transfer documentation
 - Pathology orders and results
 - Diagnostic imaging orders, results and images
 - Prescription and supply of medications (including dispensed medicines) and home medication reviews.
 - Details of doctors and their clinics doing the ordering and prescribing
 - PCEHR must be usable by Clinicians, we point out that this should not just be GP centric.
- GPs do not see the value in it when other providers cannot easily contribute information
 - There is little 'value add' for GPs to participate (other than to provide an 'enhanced' service to patients) because they already hold all of the information contained in the Shared Health Summary.
 - Until we can provide GPs with useful clinical information (e.g. a well-constructed discharge summary not currently available from many hospitals) they are unlikely to embrace the PCEHR.

The level of use has also been limited by the absence of a national mainstream media awareness campaign, an inconsistent approach to the implementation of the system in state funded public hospitals, community health and maternal and child health services, and the perceived disparity by disciplines other than general practice regarding access to incentives for providers from other disciplines to participate.

Quote SEMML

8. High Level Targets

- Aged, chronically diseased, newborns, indigenous.
- Chronic disease management is particularly challenging for people who have lived long-term with HIV, as well as for their health providers. In trials that have targeted specific patient groups such as those with HIV, there has been a high level of signup to PCEHR.



- Targeting of **'at risk' populations** for PCEHR participation and Shared Health Summaries
- There are some clearly defined groups of patients within our community where the sharing of clinical information via the PCEHR will provide significant and early benefits both for individuals and the system as a whole. These groups include patients who have moderate and severe chronic disease, those with significant mental health problems, those who regularly receive services from multiple providers and those who assess services at the highest levels i.e. 'hospitals frequent flyers' and those who reside in residential aged care facilities.
- Providers, particularly GPs, should be supported in using clinical audit and other tools, such as patient registers, to systematically identify those in their patient populations that would benefit most from a shared health summary. It is also important that the broader eHealth community such as allied health and community health are supported in accessing this information.
- Smart applications that provide for best practice care planning, decision support, clinician collaboration and communication that work with the PCEHR are also showing great potential for providing significant improvement in outcomes particularly for patient with complex chronic health conditions who are high users of health care services.

9. Design, Usability & Expectations

RDAA has received some positive comments from members who are using the PCEHR and who have now got to the stage where they are able to upload patient records efficiently. One doctor commented that "the manner in which the whole PCEHR was set up was certainly insanely expensive, complicated, poorly explained and time consuming – However, now that my practice is PCEHR ready, the actual process of sitting down with the patient and uploading Patient Health summary is really very simple..."

Quote - RDAA

Clinical Needs

Clinicians need to know that they are viewing a complete record if they are to rely upon the PCEHR for clinical purposes.

A system that does not allow for a health practitioner to 'customise' the information they require in the care of their patient is one that is clinically irrelevant and does not support the 'patient-centred' care model.

The low level use by health care practitioners in clinical settings is directly related to the clinical relevance of the record. If what is provided and available in the record is not clinically relevant, has large gaps, or is not available in real-time to the health care professional, its use will always be compromised. Currently, patient data held within the PCEHR is not clinically relevant for health care practitioners.

- Clinical data should be clinician controlled; clinicians have a legal, professional and ethical responsibility to provide accurate clinical information.
- Redesign the PCEHR based on effective clinical consultation and a business case that includes time spent on e-health activities.
- PCEHR currently does not provide data that is clinically relevant to the health practitioner, there is a distinct lack of meaningful medication history data.



- Improve access to the data provided in the clinical document to enable greater interoperability, including the ability to group, sort and filter on key data elements.
- Support for practices with data cleansing to prepare for the PCEHR – for many practices the quality of their clinical data is the major barrier to their participation in any eHealth initiative.
- The inability of GP desktop software to search and flag that a patient has a PCEHR and upload, view, download and print from the PCEHR.
- Support for clinical applications that work with the PCEHR
- The first thing that GPs see when they open the PCEHR is a lengthy list of documents that are mostly Medicare Australia and Pharmaceutical Benefits records, which are of no clinical interest.
- Clinicians take no account of patient diary input.

Medical Specialists

- Medical specialists are extremely diverse in the technology environments in which they operate; some remain firmly planted in paper based practices where computers are used as sophisticated typewriters through to the other extreme where practices are totally paperless with sophisticated secure electronic messaging and records systems. Specialists also operate in multiple environments, in the morning a specialist may be working in a highly computerised hospital department and in the same day they may be seeing patients in shared private rooms with very little IT infrastructure.
- It is difficult to easily group the expectation of Medical Specialists given their diversity but overall it is suggested that they want their clinical and business systems to be to communicate with other providers, particularly GPs and Hospitals, and be able to access information across a range of practice settings e.g. private rooms, public hospitals and outpatient departments and private care providers such as day hospitals.
- Currently there is no PCEHR functionality which adequately supports the workflow of Specialists
- Both the eReferral and Specialist Letter workflow and content designed for the PCEHR are not fit for purpose

Allied Health

In reality, it is the nurses and midwives in any health or aged care setting who will take the time to input data into the PCEHR system. Data input requires understanding of clinical matters and therefore cannot be delegated to administrative support personnel

Quote ANMF

- Access to compliant clinical software is a major barrier for allied health, and other non-GP community based services.
- Consideration should be given to how the software industry and allied health can be supported and given incentives to develop and install PCEHR compliant software.
- A clinician portal, should be developed to enable allied health practitioners to view and upload shared health summaries.
- The recording of Nursing Care Plans should be catered for.



- Ensure all conformant software enables Registered Nurses (as legislated) are able to connect and fully utilise the PCEHR during consultations with consumers.

The biggest barrier towards greater uptake of the PCEHR by allied health is that it focuses on the primary care sector and in particular general practice. This has resulted in the dominance of general practice softwares at the expense of software relevant to other health disciplines (allied health, medical specialists and dentists), and has meant that the PCEHR is increasingly becoming an online medical record rather than a tool for multidisciplinary care and collaboration.

Quote AHPA

- There are significant features of the PCEHR which have not been realised, including the ability for allied health to have input into the Event Summary and Discharge Summary across various care settings (acute through to community) and to share these with relevant clinicians including other allied health. This lack of “horizontal integration” of patient care is a significant barrier towards meeting the goal of multidisciplinary care and collaboration.
- The uploading of Event Summary and Discharge Summary should be done via the PCEHR Provider Portal through pre-determined fields rather than through clinical management software. The Portal is currently view only, and as such has serious drawbacks in its utility. This would overcome issues such as interoperability between various softwares and enhance access for patients and clinicians in non-metropolitan areas.
- Absent the involvement of allied health practitioners, no PCEHR can ever be comprehensive, thus reducing its clinical effectiveness.
- With Psychologists currently unable to contribute towards the PCEHR, the psychological health and wellbeing of patients may not be readily shared with other members of the provider community. This means that the PCEHR risks becoming an online medical record rather than a tool for multidisciplinary care and collaboration.
- Write access is required to the provider portal for allied health, specialists and other healthcare providers who do not have access to conformant software.

General Practice / Practitioner

General Practice has an expectation that other health care providers will work with them to enable the effective, efficient and timely two way exchange of relevant clinical information about their patients, so that an effective clinical handover of care is achieved.

They expect that their clinical and business systems will interface seamlessly with external information repositories and systems, and that accessing information held in these will enhance their clinical interactions with patients and will not disrupt their normal workflow.

- Medicare Locals continue to provide general practices with support in the implementation of new eHealth based systems.
- A large amount of effort is required by a practice to implement all the foundations to connect to the PCEHR. The workload and complications do not stop at implementation.
- Registration - difficult to register multisite practices.
- GPs gain little benefit from the PCEHR. There is currently nothing on the PCEHR that is of use to the patient’s regular GP.



- There is misunderstanding in that many patients expect the PCEHR is a replacement for their GP practice Electronic Medical Record (EMR).
- Many GP records need curation (cleansing) prior to uploading to the PCEHR – this curating records probably takes biggest time component in sending a SHS to the PCEHR.
- While the primary users are GPs, they will gain little benefit if all they can see is the same information that is contained in their desktop systems.
- The PCEHR should be extended to involve all practitioners working in professions that provide Medicare-rebated services.

The PCEHR system does not reduce the administration component that is currently sizeable to a practitioner's workload in entering and maintaining high quality data, nor does it implement any form of monitoring to ensure standardised terminology or language.

Quote GPASA

Community Pharmacy

Community pharmacy has an expectation that it will have access to relevant clinical information to assist them in their patient medication dispensing, review, management, compliance and adherence programs. They expect to be able to exchange information with other providers; this particularly includes general practice prescribing and dispensing information, which can assist in better management of patient conditions. They also need to be able to access information on patient medications and conditions relating to hospital admissions, this is particularly important for patients who reside in residential aged care facilities where community pharmacy play a very important role in medication management and supply.

Other community based health care providers

The electronic exchange of information not only provides opportunities for better clinical practice, it can reduce business overheads by reducing the need to re-load information in each provider's health records. In addition the electronic exchange of referrals etc. will reduce the burden of chasing patients for referrals required to meet requirements of Medicare Australia.

Hospitals

For many years most hospitals have operated as information islands in the large health care sea with little exchange of information particularly with general and community practice. This has led to increased costs (e.g. increased unplanned readmissions), duplication of services (e.g. duplication of diagnostic tests), poor coordination of care between the acute and primary health care sectors and, in many cases, poorer health outcomes for patients.

In recent years this has been changing as hospitals face funding pressures and recognise the benefits for their patients in better coordination of care and exchange of information between all care settings. Hospitals expect that relevant clinical information will flow from their systems seamlessly to other health care providers and they will be able to easily access information about patient conditions, medications and diagnostics.



The initial focus needs to be upon the implementation of universally available electronic discharge summaries in all jurisdictions by mid-2016. This particular functionality should provide a clear purpose and focus for the universal engagement of the hospital sector throughout Australia.

- ACIITC - Transfer Documents - A Transfer document covers food, prosthetics, cognitive capacity, dermatology, continence, medicines and updated care directives amongst others. Considerable energy is wasted in both hospitals and nursing homes in the transfer of residents/patients between one sector and the other, usually with minimal or no formal documentation. The introduction of a transfer document in both directions would simplify the exchange of information between both settings thus removing the current highly inefficient transfer mechanism.
- Medicare Locals are also working closely with Local Hospital Networks to improve integration and coordination of care and eHealth initiatives are a key enabler to this happening.
- the focus of private hospital facilities involved in PCEHR wave sites has been the delivery of services to public patients, thus the workflow related to private hospital service delivery to private patients is yet to be tested.
- For the most part, private hospitals in Australia lag behind their public counterparts in terms of eHealth adoption as it has been difficult to create the business cases internally for the significant investments required to adopt eHealth technology.
- In addition, the information required to post to the PCEHR may be held partially by the private hospital and partially by the treating Specialist.

The Patient

Patients have an expectation that they should only need to 'tell their story once' and that their health care providers will have access to that 'story' and information on their health conditions, regardless of where they work in the system.

- It is not uncommon to hear the comment from patients that they already thought their health information was available to all their care providers.
- Patients expect that their care will be enhanced by their health care providers having access to information. For example, GPs through the PCEHR will have access to comprehensive hospital discharge summaries so that they are aware of changes in treatment regimes e.g. medications changes that may have occurred in recent hospital episodes.
- Patients expect that the PCEHR will support their involvement in managing their own health care and support their health literacy.
- Patients have an expectation that the PCEHR will be a robust secure system and they will have reasonable control over their information and that it will not be shared without their consent.
- The patient enrolment process is time consuming and clunky which exacerbates the cost/incentive concerns.
- If the first view of the PCEHR (after the consumer registers) does not demonstrate any value, future use by the consumer will be very limited

The ability for consumer data entry to be combined with clinical data

- There has been little engagement and no financial support for this adoption to occur within the private hospital sector, where commercial imperatives and priorities have presented additional barriers to participation.
- few consumers are asking for it



Vendors / Private Sector

- NEHTA was specifically requested by vendors not to provide specifications or guidance on how PCEHR functions should be presented to end-users: due to differences in the way vendor software operates; and because vendors considered themselves best placed to make determinations about the user experience, this has led to high levels of variability in implementations and clinician concerns about usability.
- NEHTA currently has a programme of work under way in collaboration with software vendors to address these concerns, referred to as the 'Clinical Usability Program'.
- Greater flexibility for vendors to respond to end user concerns.
- Improve the quality, usability and scope of clinical and consumer technology applications. This requires; addressing the cost and red tape associated with external developers, linking applications to the PCEHR infrastructure, opening up repository based solutions, development of consumer portals to facilitate streamlined integration with PCEHR compliant solutions.
- Support private enterprise to develop and roll out key components of the PCEHR.
- Private enterprise should be supported to develop the systems and functionality
- The private sector will play a pivotal role in both supporting the use of the PCEHR and exploiting it through the development of 'smart' applications, particularly in the area of chronic disease management, that will provide better information flows and coordination of patient care.
- Define a framework and industry security standards within which the software industry can innovate
- Software vendors should be given greater opportunity to have input into the design of the interfaces that will be presented to the end user.
- AHPA - It is vital that all health professionals are able to communicate securely with other clinicians and to securely transmit clinical information such as referrals and reports. This could be addressed by one of two options: A. Expansion of the secure message delivery (SMD) interoperability to cover all clinical information and management software. This could be achieved through the releasing "end source codes" for the PCEHR so software vendors can map their messaging capabilities to the PCEHR. This would allow the PCEHR to be the interface for secure messaging (while some software are already interoperable, the PCEHR has the true potential to enable communication and enhance clinical outcomes across all platforms); or B. A dedicated business to business channel or API/widget that allows clinical information and management softwares to securely communicate with each other. While option A is more attractive from a PCEHR utility point of view, option B will overcome issues such as intellectual property rights associated with the PCEHR inherent in option A.

Registration & Maintaining Data Integrity

- Nurses in general practice play a key role in the initial assessment of consumers, in the management of chronic disease, and in care coordination. Practice nurses will play a crucial role in educating and informing consumers about the eHealth record, and in ensuring quality, up to date data is entered on these records.
- Practice nurses are well versed in data cleansing and quality data coding, and in many practices they will carry the lead responsibility for good data transfer with uploading of information to eHealth records.
- General practice nurses can play a key role in assisted registration for the personally controlled eHealth record, and in the cleaning and uploading of data to the shared health record, given the perceived need for rapid uptake of the eHealth record and good understanding and leadership by health professionals



- Nurses already play a key role in the maintenance of consumer health records, particularly through their significant role in care coordination and chronic disease management in the general practice setting. Nurses working in general practice also play a central role in childhood and adult immunisation, wound care, and the delivery of other types of care which require ongoing documentation. General practices often rely on nursing staff to ensure quality and consistency of consumer record management.
- Medicare Locals are undertaking for the PCEHR:
 - Conduct practice eHealth readiness assessments
 - Configure practice systems to ensure eHealth ready e.g. Health Identifiers and importing Nash NKI Certificates
 - Supporting eCollaborative initiatives – about half of the shared health summaries have been uploaded by eCollaborative practices
 - Assist practices with clinical data aggregation, data cleaning and clinical audits
 - Assist practices integrating healthcare identifiers into electronic practice records, data records and clinical coding to ensure accurate uploading of information to the PCEHR
 - Assist practices to upload shared summaries into the PCEHR system
 - Assist practices with PCEHR registration training
 - PCEHR Training, seminars and webinars – Individuals, practice based and group training
 - Consumer awareness and developing resources for consumers
 - Implementation of, and support for, secure messaging
 - Respond to inquiries re Medico-legal issues, privacy, clinical benefits, integrating eHealth into existing workflow
 - Support practice teams on the process of validating patients' individual health identifier
 - Support clinicians in creating a shared health summary and uploading to a patient's PCEHR and downloading event summaries from PCEHR into the patient's record
 - Providing telephone and email support to practices
 - Development of eHealth resources including practice eHealth policies and clinical software templates
 - Regular eHealth focused articles in ML publications.

Workflow

- The absence of specific remuneration for medical practitioner contribution to the PCEHR reinforces the need to ensure that using PCEHR functions does not impose any additional workflow requirements on them.
- Where possible, the system should enhance established workflows of clinicians rather than disrupt it.
- Greater involvement by key user groups such as clinicians and nurses is required to help re-engineer its functionality and useability.
- The rigid framework of the existing user interfaces does not recognise individual workflow practices.



- Define two or three key clinical workflows that will save the doctor time or money
- Greater flexibility / user customisation required to suit individual clinician work practices.
- Providing an edit function would help make the process of maintaining a current SHS more efficient.
- Review the work processes for General Practice, in particular introducing the SHS clinical document and provide tools for maintaining the accuracy of this information in an efficient manner.
- Support for the development of a more user friendly solution for health care practitioners through tighter integration with existing clinical software including decision support tools.
- Re-engineer clinician-faced functionality to ensure it can reliably and accurately automatically capture and provide the information and is fully integrated with clinician workflows
- Specific workflows should be focused on and preferably those where increased adoption would quickly deliver an improved health care outcomes and repay the taxpayers investment. Training and incentives could then be targeted on these workflows.
- The system is complex to navigate and rather than acting as an enabler, it inhibits practitioner efficiency.
- Data in both the header and the content must also be stored in a format that is searchable to facilitate ease of use.
- There has been a tendency to assume that e-health applications in Diagnostic Imaging can be copied from Pathology models, on the basis that both specialties are 'diagnostic' medical disciplines. This has neglected the very different work flows and data types associated with each specialty, particularly around the integration of images and reports in Diagnostic Imaging.

Other

- Medication management and the holistic and seamless sharing of pathology and radiology results needs to be properly addressed so that a much richer functionality and usefulness of the PCEHR
- The PCEHR should enable the inclusion of data from medication management services and primary health care services provided to patients by community pharmacists.
- Shared Health Summary (SHS) currently cannot be edited over time.
- A simple, accurate and accessible electronic shared health summary is the foundation of a clinically adoptable PCEHR. The key components of a meaningful shared health summary are patient allergies and adverse events, medical history, medicines and immunisations. Currently, shared health summaries do not interact with the patient's local electronic health record within GP desktop clinical information systems.
- The uploading of Event Summary should be done via the PCEHR Provider Portal through pre-determined fields rather than through clinical management software.
- Additional functionality in particular the incorporation of pathology results and diagnostic imaging results
- documents are not presented in an accessible way. Documents are listed, but there is no way of knowing what is in them unless they are downloaded individually, resulting in additional time and effort.
- There is no facility for the practitioner to amend or remove the document.
- in a patient with a chronic health condition, how far through the documents in the PCEHR does a practitioner have to go, and how long does a practitioner need to spend to find relevant information?



- there be a facility to amend an uploaded document
- Alternatively facilitating direct upload through a secure portal would avoid the need for more expensive software development.
- There has been no real assessment of the state of readiness of the public pathology sector (including Laboratory Information Systems, EMR). Further engagement at a jurisdictional level is required to help progress this.
- There should be stronger standards for discharge summary preparation and involvement of public pathology in the roll out.
- Electronic discharge summaries from hospitals are crucial and their provision can be targeted and measured.
- The availability of pathology, radiology and medicines dispensing information in the PCEHR would also add particular value for rural and remote health consumers as they move across the health system and a range of health providers who are not local or regular providers of care.
- For clients involved with a community palliative care service an afterhours telephone triage service is a requirement. Triage services in Victoria have access to the PalCare -- Client Management System and can add notes if the client or carers ring with an issue. Clarification needs to be made about the role for these types of services and the information in the PCEHR.
- The PCEHR does not allow uploading of the Advance Care Directive. This negates the idea of reasonable and timely access to a care directive aimed at those administering immediate and in some cases emergency care to a dying patient. It is vital that the advance care plan is uploaded to the PCEHR
- It is generally agreed that there is a significant need for simple, secure access to images and reports to plan patient management (including any further testing) and avoid the cost, inconvenience, and radiation exposure of unnecessary repeat examinations. This would require a nationwide registry of Diagnostic Imaging examinations, which could be supported by the PCEHR.
- It is also not clear how individual providers working within larger organisations will view the provider portal unless their wider organisation agrees to participate. For example, a dietician working within Monash Health cannot get provider portal access without some prior commitment from Monash Health to participate.
- Medicare data is also displayed as a long list, which requires much manipulation to be useful.
- Ensure key clinical documents can be sent to the PCEHR – discharge summaries from all hospitals, specialist letters, allied health event summaries, radiology and pathology reports, and care plans.
- Development of electronic care planning functionality in PCEHR as part of a flexible capability to utilise a rich suite of documents through the system.

Advance Care Directives

- PCEHR aims to achieve storage of Advance Care Directives in an individual's eHealth record.
- Advance Care documents may have multiple parties involved in their development and review, and potentially with multiple signatories being provided for completed documents. Documents may be developed in collaboration with assistance from lawyers, healthcare providers, family members or aged care facilities. This approach has potential to cause confusion for consumers and health providers. Currently there is no way of knowing whether the latest Advance Care document held by the PCEHR is in fact the latest Advance Care document.



Telehealth

“Telehealth provides financial incentives to eligible health professionals and aged care services that help patients have a video consultation with a specialist, consultant physician or consultant psychiatrist. Telehealth aims to remove some of the barriers to accessing medical services for Australians who have difficulty getting to a specialist or live in rural and remote areas.”

<http://www.medicareaustralia.gov.au/provider/incentives/telehealth/>

- In regional, rural and remote areas healthcare can be facilitated and optimised via telehealth.
- Improve access to care for rural and remote patients via enhanced data sharing accompanying telehealth consultations.
- Supporting other primary care initiatives that use eHealth as an enabler for broader primary health care change and improvement, e.g. telehealth.
- Build on shared care arrangements with specialists and develop that relationship as the basis for sharing data (as exemplified by telehealth).

Secure Messaging (Secure Message Delivery – SMD)

- Standardised secure electronic messaging and health identifiers to communicate with other software systems in the health care sector is a key foundation step before effective technical integration between systems and utilisation of the PCEHR infrastructure across all software in the health care sector can be achieved.
- The SMD interoperability needs to be expanded to cover all clinical information and management software. This will help enhance interaction between providers and GPs and use of PCEHR then becomes practical and logical. The priority should be focussed more on the secure and EASY movement of medical information between point to point.
- The SMD interoperability needs to be expanded to cover all clinical information and management software. This will help enhance interaction between providers and GPs and the use of PCEHR then becomes practical and logical.
- Increased emphasis on information flow electronically between the patient’s GP and other healthcare providers and their organisations point to point using national standards for clinical documents such as a referral, prescription, pathology and diagnostic imaging order and result and a discharge summary. Consideration should be given on how functionality can be built to support information sharing between healthcare providers for all clinical information known about a patient.
- Shared electronic health records and the use of secure messaging should be the cornerstone of team based care. If information is not flowing electronically today between the patients’ healthcare providers then it’s a stretch to implement this for the PCEHR.
- The widespread adoption of a fully interoperable point to point secure messaging service would provide significant and immediate benefits to both patients and clinicians. It will also support the operation of, and be consistent with, the PCEHR in that it will ensure that information is exchanged electronically between care providers and that their health records are populated with the appropriate information needed to drive health summaries etc.
- Whilst the implementation of a fully interoperable point to point secure messaging system can provide early and significant benefits to the system it is not the desired end point which is a comprehensive and integrated Health System. Messaging will provide for more efficient



exchange of information but it is really only automating a manual process e.g. sending a letter with patient results to a practice, it does not in itself reform the way that care is provided i.e. what do we do with the message.

- Members of the AML Alliance General Practice Forum have been particularly vocal in their support for effective secure messaging services as demonstrated by the **quotes** below:
- Improve multidisciplinary care and collaboration by increasing point to share utility within the PCEHR
- There is very little installed capability for secure message delivery to drive the flow of information needed to supply the PCEHR, and permit access to and processing of the information it holds.
- The lack of access to Secure Message Delivery (SMD) enabled software for access to the PCEHR, in both public hospital and private practice settings

"I believe that reliable, secure communication between primary, secondary and tertiary care providers is the foundation upon which the PCEHR should have been built."

"...the rapid adoption of a useful "eHealth" environment for general practitioners (requires) an interoperable (open) secure messaging system. This should be the top priority, the technology exists and already has a large but not complete uptake...it requires a whole of health care approach, separate, to the PCEHR, which seems to have completely ignored our specialist colleagues."

Quote Australian Medicare Local Alliance

- Secure point to point messaging will allow clinicians to exchange information regarding patients (e.g. referrals, discharge summaries, reports, etc.) in a way that is timely, accurate and fully integrated with their clinical record systems. It will reduce duplication, provide for better clinical handover and co-ordination of patient care and reduced the administrative effort and costs.
- A range of solutions are already available and the software industry should be supported and encouraged to deliver a standards based, economically efficient, secure communication environment that allows health care provider organisations to safely exchange clinical information and also to communicate with national eHealth infrastructure services such as the Health Identifiers (HI) Service, and National eHealth Record system.
- Whilst a majority of general practices have already installed secure messaging services many of their specialist colleagues, with the exception of the diagnostics specialists, have yet to adopt secure electronic messaging, this is also true of most allied health practices. These providers should be encouraged and supported to adopt systems that support secure electronic messaging or at the very least be able to access a secure web based portal for exchanging messages. The same is true of allied health and secure messaging will provide an opportunity for them to participate in the eHealth reforms particularly if secure web portals are developed that allow two-way communication between allied health and general practice.
- 2008 COAG eHealth Strategy
The original 2008 COAG eHealth Strategy outlined the "priority solutions" with "electronic information sharing" (including test ordering and test results reporting) being listed in the first grouping of solutions. These priorities have not yet been implemented and in a perplexing



decision many of these activities were stopped or deprioritised in 2012 in favour of other PCEHR activities.

10. ECLIPSE – An alternative platform for PCEHR

- The clearly stated goal of leveraging off existing IT system capability where possible as outlined in the National eHealth Strategy has not occurred in the case of the PCEHR.
- The Commonwealth already possesses a robust and extensive platform upon which the PCEHR could be leveraged,
- Resulted in the massive cost blowout for the system due to the profligate construction of yet another unnecessary stand-alone system
- Existing Commonwealth IT capability could have easily been leveraged by creation of a PCEHR 'module' as an addition to the ECLIPSE system.
- Existing ECLIPSE infrastructure and systems' capability is highly sophisticated, robust and secure. It can easily incorporate the requirements needed for the capture eHealth record information from many sources/systems, and it has the ability to transmit it securely to third party software systems for presenting the eHealth record information to the users
- The ECLIPSE Working Group has had the benefit of having very capable staff in its Secretariat, and any changes to the funding of this program and its staffing would not only be disastrous for ECLIPSE it would make implementing the rational approach of incorporating the PCEHR into the ECLIPSE framework extremely difficult if not impossible. This would doom eHealth in Australia to the current siloed approach to the management of healthcare data and IT systems at DoH, which is the cause of so much private sector frustration, economic waste, and total lack of interoperability.
- One of the ongoing arguments, which have consistently been discussed with NETHA, is that ECLIPSE transmits clinical data and should have been included in the development specifications for the platform. Unfortunately ECLIPSE was seen as a billing system and a totally mutually exclusive system, and our input explaining that this is not the case was ignored.
- Leveraging of existing systems makes sense, as well as meeting the requirements and aims of the National eHealth Strategy. One of the ongoing arguments consistently put to NETHA and the Department of Health is that ECLIPSE could provide a unique platform, which could have been used in the development specifications of the program, as it transmits up to 80% of the clinical data required.
- ECLIPSE is used by all PHI funds, and is supported by the majority of Hospital providers as their preferred clinical and administrative system.
- AHIA is concerned that Medicare Australia's ECLIPSE system has not been seen as part of the PCEHR infrastructure and design as our understanding was that where possible, the PCEHR would draw upon data within existing systems and infrastructure. ECLIPSE is utilised by over 95% of the PHI and is supported by the majority of Hospital providers as their preferred clinical and administrative system.
- AHIA is concerned that there is no mention of health information held by Private Health Funds as data repositories even though Health Funds have data on Hospital and Allied Health services for over 11 million Australians
- Health Funds maintain information on services for the purposes of verifying claims and paying benefits for all individual members.
- Funds are also provided with HCP (Hospital Casemix Protocol) data which provides clinical information down to a DRG (Diagnosis Related Group) level.
- That is Funds already have considerable amounts of information relating to their individual members



- The AHIA believes that this information should be included in the PCEHR so that individuals have a complete picture of their health records. This would ensure that there are no gaps in an individual's record
- APH - Eclipse: In light of the current state of eHealth adoption in the private sector and the financial hurdles to participation, the private hospital CIOs and the private health insurers have raised the question as to why existing infrastructure such as Eclipse has not been leveraged as both a platform for communication and in providing valuable private sector episode information to the PCEHR, much the same way as MBS data is utilised today. The private sector has already invested heavily in connecting their systems to Eclipse and ensuring its adoption, but these requests to the National eHealth Transition Authority (NEHTA) and the Department of Health have not gained any traction.

11. Education / Training

Practice Environment

The lack of a 'practice' environment that is easily accessible from the desktop would assist healthcare practitioners to become familiar with the PCEHR environment before they use it in a clinical context. This is a common feature available in general practice software and provides a system where clinicians and reception staff can go into the simulated patient environment and become familiar with all the benefits and inherent workflow issues.

- **Develop curriculum templates for educators** that are supported by simple "plain-English" education materials that are targeted and customized for individual users groups.
- Include PCEHR education in AMC accreditation programs.
- eHealth staff unable to deliver practical clinician training.
- There is misunderstanding in that many patients expect the PCEHR is a replacement for their GP practice Electronic Medical Record (EMR).
- Consideration needs to be given to assisting and resourcing health care practitioners to be 'advocates' and 'educators' for the PCEHR with their patients.
- No doubt amongst respondents to the HISA/HIMAA survey was the importance of the role of professional associations in the clinical and eHealth sector in providing education, training for and engagement with the PCEHR's critical stakeholders.
- Medicare Locals to date has been working with their local health care providers to support them preparing for and implementing eHealth technologies. Before any clinician can use the PCEHR they need set up their systems, both human and technology based. Medicare Locals work with practice staff to implement the main foundations for eHealth, including:
 - Clinical Governance;
 - Improving practice data quality;
 - Clinical and health informatics workforce training;
 - Obtaining individual and organisational healthcare identifiers;
 - Obtaining and installing National Authentication Service for Health (NASH) Public Key Infrastructure (PKI) certificates to so practices can access the PCEHR; and
 - Ensuring that the practice has eHealth compliant systems.
- Assisting Medicare Locals to increase healthcare professional and consumer awareness and understanding of eHealth, its benefits and their role.



- Supporting Medicare Locals in increasing the readiness practices to implement eHealth technologies and implementing foundations for eHealth, including healthcare identifiers, data quality, compliant systems and secure electronic communication.
- Lack of investment in tertiary level programs and creation of positions in health and aged care facilities for health informaticians

12. Incentives

Clinician uptake of new electronic clinical documents (Shared Health Summary or Event Summary) will remain low if there is no incentive to include this in a patient's consultation.

For general practice at least, much of the information that is to be included in the PCEHR is already available for their current patients on their clinical systems so at this stage there is not a strong clinical or business case for using the PCEHR whilst other providers have yet to adopt the PCEHR.

- The government needs to ensure that funding programs such as the Medical and Pharmaceutical Benefits Schedules and Practice Incentives Programs are designed with eHealth in mind and will drive the uptake and use of eHealth initiatives.
- Support for better interfaces between the primary health care sector and the acute care sector (hospitals).
- The lack of appropriate financial or compliance (e.g. accreditation) levers to drive clinical adoption and use.
- Implement a properly considered and sustainable commercial model for key stakeholders involved in the scheme (including government, clinicians and the IT industry). This is necessary to stimulate innovation and drive sustainable IT investment in the national eHealth agenda.
- Lack of a value proposition or relevance
- Lack of financial incentive to the General Practice (as apposed to general practitioners)
- training costs, remuneration for uploading information
- ART (assisted registration tool) requires dedicated staff time.
- Incentivise specialist uptake of eHealth records and continued support of standardised secure messaging and clinical information exchange between care providers.
- The provision of incentives should be a fundamental component of a more private sector driven eHealth environment.
- There needs to be an incentivised business model for pharmacy support, and encouragement for pharmacies to change their workflow to ingrain the scanning of barcodes on all available electronic prescriptions.
- Supporting peak NGO's to resource and educate their members to engage with their patients in relation to the PCEHR
- A lack of funding to support pharmacy-specific eHealth education and pharmacy-wide capacity building
- The fully funded Electronic Prescription Scanning Incentive announced by the previous government should be confirmed as soon as possible by the new government, in recognition that Electronic Transfer of Prescriptions is essential to the national medicines repository and the future move to a paperless prescription environment.
- The current agreement with Medicare Locals to engage with pharmacies to sign them up to the PCEHR should be reviewed and reallocated to the Guild, which has the experience, knowledge, influence and national focus to deliver more cost-effective outcomes.



- Incentivise Specialists to use a CIS to improve uptake of electronic patient records across the system.
- Consider linking MBS rebates with eHealth contributions - e.g. make it a MBS requirement for reimbursement for pathology and imaging data/reports to be delivered electronically to a shared EHR. Consider no PBS authority drugs are available to a patient without a shared EHR.
- Concerns still exist over the cost of testing, ongoing conformance and the cost of maintaining and supporting the interface, this is exacerbated as there have been numerous changes in both requirement and scope along the journey; it is uncertain who in aged care could afford to absorb these costs and why they should have to.
- Many health providers can see the potential clinical benefits that will come with a national eHealth record; however, many remained to be convinced that a strong business case exists for investment particularly as their precious clinical time could be diverted.
- For many practices there is a very significant investment in time required to 'massage' and cleanse their data so that it is in a form that will allow easy uploading to the PCEHR.
- Consideration should be given to how the broader medical software industry can be supported and given incentives to ensure that their clinical and business products are PCEHR compliant.
- The current funding provided to Medicare Locals to support local clinicians and practices for the implementation the PCEHR will cease on 30 June 2014. Without the on the ground support provided by Medicare Locals to practices and clinicians in implementation of eHealth initiatives, including the PCEHR, it is likely that the implementation will stall and even go backwards. eHealth works best when it is a part of a suite of health care activities that seek to improve the patient journey and connect care; Medicare Locals are ideally placed to support eHealth in the context of the wider health care environment.
- GPs must be adequately reimbursed for the extra time taken to curate the patient's electronic health record. A simple way to do this would be through a specific Medicare item number for this task. This alone would almost certainly boost the number of Shared Health Summaries being uploaded to the PCEHR.
- Unlike GPs, physiotherapists have not received government support through programs such as Practice Incentive Program (PIP) and ePIP to assist in the computerisation of practices.
- there is no payment for health practitioners to curate the SHS and upload it outside a consultation with a patient, because the Medicare benefit only applies to work done on the PCEHR during a consultation.
- a Medicare benefit be payable for work done curating a SHS or other document, outside a consultation and without the patient having to be present
- the time it takes to curate a SHS, obtain and document the necessary consent in the patient's medical records and ensure that the information in the SHS is up to date before uploading it
- although GPs can charge a long consult, it is not always feasible to extend consultations if there is a busy waiting room
- the time taken to cleanse data in a clinical record before including in a SHS. There is no payment for this, outside a consultation with the patient.
- There is a precedent of providing support to medical practitioners to meet compliance requirements for the PCEHR through software development and direct practice incentive payments but this benefit has not been extended to allied health practitioners.
- With this in mind, two of the major areas of concern that must be addressed are the lack of incentives/support for general practice to participate, and the need to resolve fragmentation of patient health information.



- There is no specific MBS item number allocated for practitioners' time in relation to the PCEHR and ⁽⁶⁶⁾given the extensive discussion that is required in relation to its use; this is a further disincentive for ⁽⁶⁶⁾medical practitioners.
- For example, the Danish model has significant financial incentives which drove its adoption. Quicker payments to be allocated for physicians who use electronic health records (EHR) and financial incentives were given to primary care practices for phone and e-mail consultations.
- There are a range of MBS items that could be varied to favour or be conditional on uploading of a health summary or use of the PCEHR including enhanced primary care items for chronic disease
- The practice nurse incentive program could be tailored to include incentives for rural and remote practices to better use the PCEHR.
- The Medical Specialist Outreach Assistance Program should be updated to include an expectation of electronic communication.
- maximisation of jurisdictional incentives to ensure the provision of electronic discharge summaries, for example through hospital accreditation processes or Activity Based Funding arrangements.
- clarify the business case for primary care providers
- there has been insufficient funding to support public health services in covering the cost of PCEHR implementation in the near term.
- There is currently limited funding available to pay the upfront investment needed to construct the necessary infrastructure.
- Initial investment costs include software procurement, human resources, technology development, training, and the costs of developing metrics to measure
- The level of initial investment required is compounded by the inadequate (or non-existent) ICT infrastructure of many health services.
- A lack of technical ICT capacity for many health services is acting as a barrier to adoption
- Due to the absence of a specific item number, many GPs are unwilling to bill an MBS item for preparing and uploading a shared health summary as they are concerned regarding compliance and an audit.
- Change and adoption being resourced is a critical part of the success of eHealth in this area and indeed across the board.

ePIP (Practice Incentives Program)

- Supporting Medicare Locals to assist general practice to meet the requirements for the Practice Incentives Program eHealth (ePIP).
- Appropriate incentives such as the ePIP should continue to be in place to 'compensate' for the costs and time involved in preparing PCEHR ready patient records. Medicare Locals should also continue to support their providers in this task through supporting the use of clinical audit tools and initiatives such as the Australian Primary Care Collaboratives.
- Medicare Locals have also worked closely with general practices to reduce the paperwork burden on them, in particular complying with the requirements for the ePIP.
- Assistance with ePIP registration through Medicare
- ePIP - very little money flowed and it was seen as more work than it was worth.
- The vast majority of clinical management and information software used in the primary care sector is focused on general practice, and not suitable for allied health professionals, dentists



and medical specialists. This has been driven, in part, by government investment in general practice (e.g. ePIP). Consequently, the lack of incentives and support for allied health, medical specialists and dentists has created an uneven playing field between the various clinical groups and ultimately undermined the utility of the PCEHR.

- The eHealth Practice Incentive program could be targeted to provide incentives for rural and remote health care providers.
- Without the intensive support provided by Medicare Locals throughout the eHealth Practice Incentive Program (ePIP) registration phase, it is unlikely that General Practices would have met the requirements to receive their payments due to the ePIP process preceding extensive GP education efforts by Medicare Locals, the complexity of the registration processes, and the prohibitively short timeframes afforded by DHS/Medicare to complete the process.
- The ePIP process also deflected support staff away from broader more strategic provider awareness raising, education, registration support, and training for private specialists and allied health, which has had a detrimental impact on the utility of the system to the early adopting GPs and consumers.

13. Privacy / Security

Experience of the initial rollout of the PCEHR demonstrates that the overwhelming majority of consumers give blanket consent at registration for the full range of information to be uploaded and for data to be accessed by all relevant health professionals.

- Resolve legal, governance and privacy concerns (whether perceived or real)
- There is significant concern about the privacy of data on PCEHR and its potential misuse.
- The system is not secure if the information cannot be kept confidential.
- A simple outline of the entities, rules and processes that govern the privacy and security of the personal information within the PCEHR
- Public clarification is required on;
 - How the system is monitored and by whom
 - Online network security
 - The legislation that regulates the use of information
- Patients need to understand how it will affect them and how to use it to improve their health outcomes.
- They need to have confidence that information about their health status is appropriately stored, managed and accessed.
- Personally controlled elements of the PCEHR system that are currently available, such as the ability to withdraw consent for records to be uploaded, to block access to their record and to upload consumer-entered information are fundamental to the consumer.
- Consumers have expressed the importance of being able to choose who can access to their record and the particular records that will be contained in it.
- Privacy concerns relating to the sharing of information relating to stigmatized conditions such as HIV, or behaviour that can potentially attract criminal sanctions such as illicit drug use or sex work, may impede adoption.
- The inclusion of provisions enabling consumers to mark a clinical document as 'no access'.



- PCEHR legislation does not exclude the Insurance industry from obtaining individual Health Identifier (IHI) numbers and possible new linkages between the individual's PCEHR information and their health insurer. Patients/Consumers are anxious because insurers are not medically qualified to read or interpret health records and information may be incorrect and read out of context by a non-clinical person, potentially misinterpreting the record and increasing some health insurance premiums.
- Support for the PCEHR will be enhanced if development is seen to be informed by international best-practice (for example OECD work regarding the privacy aspects of EHRs)

A greater focus is required on technology's security standards. The PCEHR has defined document standards for several health events. It has not yet defined a security standard that encompasses the entire process. This means the entry point for the system data is not controlled, only the transport security, which leaves the system compromised. It is equivalent to EFTPOS defining a security standard without defining the device parameters so any device can be attached. Recommendation

Quote HCN

14. Governance / Standards / Terminology

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

Quote CeHA

The PCEHR Concept of operations refers frequently to the importance of governance. It quotes seven governance principles from the National eHealth Strategy including transparency, accountability, appropriate stakeholder representation, sustainability and the balance of local innovation and national outcomes. These principles were not followed, and the result is that a good plan failed.

The PCEHR should seek to integrate effectively with existing systems, across Australia's jurisdictions including public, private and community-based networks.

There are aspects of national infrastructure management such Health Identifier (HI) Service, National Authentication Service for Health (NASH), Secure Message Delivery (SMD) and the Conformance, Compliance and Accreditation (CCA) process which are too complex, hard to navigate without support, do not consider market or private sector drivers and add considerably to the expense of participation.

This creates significant additional barriers to the adoption of national infrastructure and standards in the private hospital sector. The sector understands the requirement for systems to be safe and secure, but this needs to be done without overburdening industry. A more appropriate authority is required to manage this with proportional participation from the private sector.



Change Management

- Implement a formal, transparent and authoritative change management process that is developed and executed with industry involvement.
- that high and immediate priority be placed on the engagement of professional associations and colleges in general and health information professionals in particular in the change management process required to ensure adoption of the PCEHR and enable its vital contribution to health reform success.

Who

- The government's role in the eHealth system should be limited, focused on developing appropriate essential standards required for security and data interchange, with the requirements of vendors and end-users being the primary consideration in this process. The government should also maintain the essential national infrastructure required for authentication, and ensuring an appropriate privacy framework.
- Consideration should be given including people with clinical skills and knowledge along with a range of other skills in the governance arrangements for the eHealth system.
- The PCEHR relies on the goodwill of the medical profession, public and private healthcare organisations, and the private medical practice software industry. Only the public healthcare organisations are currently involved in the governance arrangements.
- The complexity of relationships between DOHA, NEHTA and conformance and compliance arrangements (e.g the CCAGG) has also resulted in a lack of transparency and clear accountability.
- The role and authority of the Independent Advisory Committee (IAC) has been ambiguous and while industry has been pleased to be involved, it has been unclear how the IAC has contributed to the PCEHR implementation process.
- Implement more representative and transparent governance of the PCEHR (and national eHealth) program, including greater industry, clinical and consumer representation on key governance forums and more effective engagement of jurisdictions to support implementation of the program at scale.
- Governance should have independence from Government, and ideally there should be an independent System Operator and an Independent Advisory Committee;
- The governance arrangements must be clear to consumers
- All user groups should be represented
- Overhaul of eHealth governance and leadership arrangements to improve transparency, accountability, consultation, strategic development, and implementation. Apply a standards based approach.
- With multiple vendors (CIS, Messaging Agents, and PCEHR) involved in the end to end solution there needs to be a centralised authority who can investigate issues noted by the user community and negotiate a resolution
- Clinical oversight and control required.
- since the handover to the then Department of Health and Ageing - now Department of Health (DoH) - governance has been reduced to essentially non-existent.
- The complexity of relationships between DOHA, NEHTA and conformance and compliance arrangements (e.g. the CCAGG) has also resulted in a lack of transparency and clear accountability.



- With multiple vendors (CIS, Messaging Agents, and PCEHR) involved in the end to end solution there needs to be a centralised authority who can investigate issues noted by the user community and negotiate a resolution
- to be an independent authority, comprising representatives from all key stakeholders
- to be at arms' length from the political and funding process.
- Strong, streamlined and transparent governance, overseen by a single entity responsible and accountable for all eHealth product design and release.
- The current PCEHR governance model lacks accountability and transparency. A single entity that carries the responsibility for both clinical and corporate governance will ensure that the eHealth product design has been through appropriate clinical assurance and gating processes before the product goes 'live'
- Legislation should not limit the number of portal operators.
- Unique Health Identifiers should be deployed throughout all regulated healthcare.
- Extend the PCEHR to all professions that provide Medicare-rebated services, with appropriate IT subsidies.

We consider the key issue preventing successful implementation is the failure of the various government agencies to act together and engage the community, both public and private, according to the clear advice to create a separate performance oversighting entity directly representing all relevant interests. The need for collaboration, and an independent management structure, was clearly set out in the Parliamentary "Health Online" report of 2001 and underscored in subsequent reports underpinning the agreed National e-Health Strategy in 2008. Many of those involved in the development process remain frustrated that the many arms of our federated governments, whilst having endorsed the obvious validity of this key recommendation, have not actioned it.

Quote CeHA

What

- When we use the term 'governance' we mean Program and Portfolio level governance, which by implication involves EVERY STAKEHOLDER to an IT system. It considers all matters relevant to that system as a collective and by necessity ensures it involves all of the stakeholders to the system. Things that are included in 'best practice' governance processes include:
 - All policy associated with, or affected by, the system
 - System Development – prioritisation of all product development, scoping concepts appropriately and gathering the actual (not perceived) business requirements well in advance of producing any system requirements or undertaking any attempts at developing code.
 - All proposed or actual system enhancements/improvements.
 - Risk Management – includes; impact assessments, risk planning and mitigation,
 - Change Management – includes of the system, but critically also for the stakeholders.



- Usability – ensuring the utility of all IT products to the end users of the system before any product or capability is released into production.
- there is also considerable confusion amongst health professionals and health organisations between the PCEHR and the SA Health initiated rollout of an Enterprise Patient Administration System (EPAS). Health professionals are unlikely to see any immediate or long-term benefits of participation in either system when it is unclear when the two systems will be inter-connected.
- The PCEHR system is based on multiple data sources stored in multiple repositories, and therefore does not address any of the fragmentation of patient medical information and streamline clinical practices.
- Australia has a cumbersome, essentially static storage system of patients' medical record silos which are still largely paper-based (requiring scanning or data entry), lacks clinical decision-making capabilities and is not designed to support dynamic interactions between members of patient care teams.
- Nor is there any capacity to benefit public health and safety through the routine capture and interrogation of clinical data, in terms of "computer smarts" that can alert providers to potential errors, pinpoint trends and identify processes/procedures/practitioners that are failing to meet standards. At the same time, enormous opportunities for fields of new medical research are lost, e.g. through clinical registries, etc.
- There is no adequate national provider directory in place.
- Robust search engines are needed as part of the PCEHR infrastructure, which would enable clinicians to filter for medical condition, subspecialty, test type, date etc.

Where

- AHIA recommends that the legislation ensures adequate security of stored data rather than limiting the options for where data can be stored (e.g. Requirement for data to be stored in Australia) The requirement to store data in Australia places limitations on potential data warehouse options. It precludes emerging and potentially more efficient and cost effective technologies such as cloud or virtualisation of servers. The security of the data in storage is paramount.

PCEHR Act 2012 / Legislation

PCEHR legislation is dynamic and subject to change by regulation not legislation. The system-operator, as a public servant, is not independent of the system but a part of it. Government agencies have the authority to share PCEHR information using the consent mechanism. Separation of oversight and governance from operational matters is essential to long term confidence in clinical and privacy practice.

Quote VCCL

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.
- and/or the relevant Regulations and Rules to eliminate any unreasonable legal sanctions on bona-fide users.



- 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.
- The prospect of Mandatory Data Breach Notification obligations more generally has been raised in legislation which was to go before Parliament
- Improved and simplified eHealth Record Participation Agreement
- Cut red tape and reduce the number of authentication certificates required by clinicians and healthcare organisations to perform clinical and government transactions.
- The PCEHR legislation does not exclude the Insurance industry from obtaining individual Health Identifier (IHI) numbers and, in the future, possible linkages between individual's PCEHR information and their health insurer.

Ownership of the System

- The Commonwealth (DoH) is the system owner, and they should take this role on both professionally and whole-heartedly. In order to do this they will need to do a number of things of which includes, but is not limited to, the following:
- Actually taking real ownership of the system, which by implication means not doing the following: Administering it at arm's length', which creates a decision making vacuum in which parties that ought to be led/directed by the owner are left to make key decisions that are the responsibility of the owner. This leads to inappropriate system development, and the creation of IT products/capabilities that do not meet the needs of the end users. It also can lead to very large waste in resources, and typically results in massive cost blowouts – witnessed by the almost \$1 billion spent to date. DoH has a reputation amongst its external stakeholders of abrogating its IT system responsibilities, and leaving it up to others to make decisions that are inappropriate and costly not only to the department - and ultimately the Australian taxpayer - but to its systems external users.

Contract Management

- writing contracts that empower the owner and provide a legal basis upon which the owner can maintain control over its IT suppliers to ensure they deliver products that actually meet the owner's requirements and specifications.
- To ensure that the systems operator (in this case Accenture) does what it's told by the system owner, which is to deliver the functionality specified by the system owner, rather than the operator delivering what it thinks/believes is best for the owner.

Standards

The process of standards development is rigorous and is based on the principles of transparency, balance of interests and consensus. Where there is agreement on broad policy matters amongst stakeholders, it is more likely that technical standards are developed in an efficient and timely manner. In the course of the development of PCEHR technical standards, we have observed the absence of agreement on e-Health policy matters amongst stakeholder. This has posed challenges to developing timely and widely accepted technical standards.

Quote Standards Australia



Wider agreement on policy matters relating to the PCEHR will lead to a collegial health informatics stakeholder community, a more effective and efficient standards development environment and ultimately a more widely acceptable and employable PCEHR platform.

Quote Standards Australia

- Any future PCEHR standards development work program must be referenced back to the accepted PCEHR e-Health policy and a clearly articulated standards development proposition which deals with the scope of the work and the intended use of the standard in achieving the PCEHR e-Health policy.
- To improve the PCEHR's effectiveness, HCN believes the original vision remains the best guide. This recommended a framework and standards to be established and reduce the need to operate large IT systems.
- The Australian Government's focus should be on developing 'high level' standards and operational parameters for the PCEHR and not seek to influence and/or control at a micro-level. This can be achieved by the Department of Health shifting its focus to managing the substantial national infrastructure created through the PCEHR project as the core through which other value-adding systems may integrate.
- recommends vesting authority for the development and maintenance of technical and professional standards and associated engagement and change management strategies in the professional bodies concerned, rather than in the private sector or in government bureaucracy.
- Government, however, should play a central role in auspicing, funding and supporting this authority and the infrastructure required for the PCEHR (terminology, identifiers, secure messaging).
- there is an argument for increasing the focus on software systems actually implementing and adopting initial standards and ensuring these are tried and tested in the field before moving forward with additional standards development initiatives. In other words, get the fundamentals - the basic standards right in the first instance.
- the lack of consistent terminology and language is a key issue that limits the progress towards increasing functionality of the system.
- Poor nomenclature
- Vendors should further enhance their software to a level 3 CDA to improve the richness of the data for improved interoperability and architecture.
- Standardised all clinical documents (layout and terminology) to support consistent interpretation of information received especially when dealing with reports from unfamiliar service providers (such as pathology reports).
- Development of a National Health Standards Roadmap with input from health informatics, clinical and industry experts.
- 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.
- NEHTA -The lack of a cohesive approach to records management significantly increases the risk of errors such as misdiagnoses, lack of awareness of adverse reactions to treatment, and the over prescribing of medications. Each year, almost two million Australians experience an adverse drug event. Clinical studies have proven adverse drug event rates can drop significantly when healthcare providers have access to a patient's medication history.
- NEHTA - Absence of a coalition of Australian Medical Colleges to lead the development of standards for eHealth. Medical colleges have proved instrumental in defining clinical information



standards overseas. Their absence is a more systemic issue raised by NEHTA's Clinical Governance Advisors and is an area for the professions to determine how they can provide leadership in this area. In England, a Professional Record Standards Development Body has been established by the Academy of Medical Royal Colleges for medicine, professional groups for Nursing, Midwifery, Allied Health, and Social Care professions, with representation from patient/citizen groups. It acts as a professionally-led independent authority to assure national professional clinical and professional record standards. These provide the basis for: eHealth system requirements clinical workflow development curricula for tertiary programs. There is an opportunity for the medical professions in Australia to adopt such a role. This would enforce base-level standards for software, support the development of national curricula to train the next generation of clinicians, and instil the PCEHR and eHealth more broadly into common clinical practice.

- Current language is the government's terminology that is not clear to the general community
- Most pathology reports and many requests are currently sent electronically in Australia amounting to hundreds of millions per annum. The RCPA and its members have been at the vanguard in developing the architecture and standards for sending pathology reports to the PCEHR and on the standardisation of pathology reporting more generally through a project known as the Pathology Information Terminology and Units Standardisation (PITUS) Project. The information conveyed in a pathology report however is very complex and the consequences of error severe. We therefore remain some way off being able to widely communicate meaning from one machine to another without the need for human interpretation. PITUS has been making significant progress toward this goal however and should continue to be supported.
- RCPA - The 2008 eHealth Strategy captured many of these points for the foundational systems including leveraging accreditation of health care providers. Since 2008, the 4th Edition of the RACGP Standards for General Practices and the most recent Practice Incentive Programme for eHealth have laid the basis for commencing the adoption (by General Practices) of health identifiers, terminology and secure messaging. Furthermore, the Pathology Funding Agreement has outlined the need for the use of healthcare identifiers in pathology records by Pathology Practices. However, the preoccupation with PCEHR functionality and adoption has resulted in the above elements not receiving the necessary attention/follow through to the adoption of the functionality and to the realisation the benefits associated with the foundational elements.
- The College recommends that Government provides support for the inclusion of standards based electronic requesting and reporting that use health identifiers, terminology, information models and secure messaging by practice software and by pathology laboratory information systems.
- The PCEHR must move from designing systems that are stifling innovation to designing standards and frameworks. The software industry can work and innovate within these. Defining a secure end to end methodology for interoperability would be supported widely by industry. It would also provide better protection for data and systems.
- Resumption of a methodical approach to foundational standards development from where it left off prior to the PCEHR announcement, to ensure appropriately sophisticated specifications emerge for pathology, radiology, care planning etc. and a well negotiated and defined standards environment to encourage broader vendor participation and innovation
- The Australian Schedule of Dental Services is endorsed by the National Coding Centre as the accepted nomenclature of dental services. This Schedule is recognised in government funding programmes and therefore should be adopted for use within the PCEHR.
- clinical data needs to be presented in an accessible, consistent and clinically useful format, using pro forma and template documents, to ensure consistency, and to assist practitioners to find clinically relevant information within an eHealth record quickly
- documents should be labelled in the system as “shared health summary”, “event summary”, “discharge summary” etc and dated to assist practitioners to identify clinically relevant information quickly



- The inaccurate and inconsistent material on the Healthcare Identifiers section of the Medicare website. Self regulated professions are eligible to obtain a Healthcare Identifier or HPI-I, however the website states only those registered with national boards may do so.
- The master index outside EMR/PAS used for the discharge summary IHI verification process should be explored for public non-inpatient pathology.
- The Securing Quality Outcomes: Systemised Access to Digital Images roadmap sets out strategies to support interoperability in Diagnostic Imaging, and the PCEHR could play a substantial role in facilitating this.
- Diagnostic Imaging
 - (1) Strategies be developed to facilitate incorporation of IHIs into Diagnostic Imaging systems, and the implementation of HL7 messaging and SMD systems, where these are not already in place..
 - (2) There be a focus on establishing a Diagnostic Imaging examination registry, which would 'know where the imaging data are', rather than on repositories of reports in the PCEHR. An imaging registry would be the most valuable 'e-Health' advance for both radiologists and referrers, providing the ability to find, call up, and compare previous images and reports. This would improve diagnosis, decrease radiation exposure in the community, and support improved patient outcomes.
- standards need to be coherent.
- the secure messaging standard did not mandate interoperability, which has left us in a situation where secure messaging products still cannot send messages to other products.
- Delivering standards based secure messaging interoperability will deliver providers what they have wanted for many years and will contribute to providers' willingness to adopt the point-to-share record system to complement and supplement their essential point-to-point communication.
- The coding between the various GP clinical systems is not standardised to SNOWMED CT or ICPC2 so the usefulness of the information held on the PCEHR from a national assessment is severely restricted and feedback to clinicians on treatment thus hampered.

Terminology

- opportunities to exploit SNOMED CT and the Australian Medicines Terminology (AMT).
- Currently the PCEHR does not exploit the standard and richness of clinical terminologies for patients or clinicians.
- the implementation of standard terminologies in the PCEHR would greatly increase the usability and the utility of the PCEHR for both patients and clinicians.
- making the information meaningful for clinicians and consumers will dramatically increase usability, utility and uptake of the PCEHR.
- Health authorities should publish a simple coherent explanation of the agreed framework of the entities, kinds of information and access and control rules that govern privacy and personal information security.
- There is a need for funding to accommodate required changes to Laboratory Information Systems to support standardised terminology and messaging specifications
- There needs to be discussion and education on use of key phrases, e.g. drug intolerance, drug adverse reaction, drug hypersensitivity, drug allergy.
- In reporting laboratory results, the identity of the laboratory issuing the result must be clear



- Standardisation of reporting terminology to ensure pathology reports are communicated in a constant, common language is essential. There must also be a standard way of classifying information (e.g. by subspecialty/discipline, date, test/group of tests and possibly results). This should be based on the work of the RCPA PITUS Project.

Computable health and medical records enable a whole-of-life chronicle of a patient's health that can then be analysed by software to support a variety of clinical, population and medical research purposes.

CSIRO Quote

- CSIRO's research has led to the development of tools that implement the entire lifecycle of terminology use in clinical information systems. These tools are now being used in the implementation of clinical information systems and electronic health records as well as by the International Health Terminology Standards Development Organization (IHTSDO) in maintaining the international version of SNOMED CT.
- allow standardised descriptions of health conditions ... in either a formal medical language for clinicians or a more informal vocabulary familiar to patients
- The Australian Medicines Terminology (AMT) is one fundamental standard that is not yet in widespread use. Effort should be increased to finalise and implement this important standard and facilitate uptake across clinical software systems.
- Currently, there is no comprehensive standard list of 'orderable' Diagnostic Imaging examinations in Australia. An Australian Diagnostic Imaging Orderables Catalogue could be developed taking into careful consideration overseas models and the Diagnostic Imaging Services Table of the Medicare Benefits Schedule. The Securing Quality Outcomes: Systemised Access to Digital Images roadmap identifies an orderables catalogue as a pre-requisite for efficient use of DI informatics.

Medications / Prescriptions

- The lack of a universally accepted and utilised identifier for medications continues to result in unnecessary risks being experienced in drug matching between systems particularly in regards to combined drugs. Further investment is required in the development and implementation of a universally accepted medications terminology or in a program that makes the Australian Medicines Terminology (AMT) implementable.
- A medication repository is vital to enabling a more collaborative health care environment. The PCEHR medication data (NPDR) currently available is sourced through Medicare (PBS data), it is administrative and therefore not meaningful or useful in an electronic health record setting as its design and the terminology used was never intended or created for this purpose (it does not provide fundamental information such as dosage and instructions, for example). This results in the data being mostly meaningless and incomplete for both the patient and health care practitioner.
- The benefits from a national medication repository will only be totally realised when all medications for all patients are always available.
- It is unclear the extent to which the Australian Medicines Terminology has been installed into clinical systems in GP clinics, or hospitals. Without a common clinical terminology, it is not possible to achieve the basic, accurate medication list required.
- Medicines management is a significant area of value that is not sufficiently supported within current PCEHR design



- Encouraging the ongoing uptake of electronic transfer of prescriptions would also improve the quality of data available in an integrated Medications Profile.

15. Legal / Liability

Existing PCEHR clinical safety governance functions need to be brought together in one place. The nature, size, structure, and degree to which this function is legislated to mandate safety is a discussion that must be had. Such bodies exist in other industries e.g. the civil aviation safety authority (CASA).

Professor Enrico Coiera, Director Centre for Health Informatics, Australian Institute of Health Innovation, UNSW

- creates a substantial medico-legal risk to the clinician, his employer and his medical insurer.
- Recognition that eHealth has the potential to highlight deficiencies in existing practices and as such may not necessarily represent new clinical risk.
- medico-legal concerns about potential penalties imposed for breaches of data security and other unforeseen consequences of making patient data available in an electronic format.
- A significant issue is single point accountability for maintaining a contemporaneous summary over time with potential for serial changes in clinical information to be missed, with the PCEHR's current download framework of PDF documents.
- There are significant issues of legal liability if one class of practitioner relies on records about a patient treated by another (or indeed more than one other) class of practitioner, when those records are not provided by those others. This is especially so if the records are mediated, or edited, or deleted, by the patient.
- it requires maximum transparency of the provenance of data and of the mechanisms employed to help minimise data errors, but also a routine, systemic expectation that patients have a role in checking, correcting and confirming the quality of data.
- Any future direction for the PCEHR should learn from the experience of the past two years and ensure that medico-legal risk is minimised through consultation with experts in the medico-legal field.
- Ultimately no one will know whether these risks are real ones until there is more use of the system, and these issues are tested in the courts or via complaints.
- Many of these risks can be mitigated with increased education of users
- the potential liability of practitioners because of the risk of inaccurate and incomplete information being on the system
- concern about the standard of care – is there a legal duty to consult the PCEHR, and if so, how often?
- the Participation Agreement absolves the Commonwealth as system operator (absent negligence) of liability, so all of the risk lies with the practice and/or practitioner. This approach has created a feeling of distrust and suspicion in some practitioners.
- The Participation Agreement is legalistic and difficult to understand for health practitioners.
- it remains unclear who is ultimately responsible and accountable for the clinical information contained in the system
- What is the duty of care for a medical practitioner or other health professional in ensuring high quality data is uploaded?



- whether professional indemnity and practice insurance policies cover participation in the PCEHR
- It is of concern that if an individual can only have a single nominated provider at any one time and an individual changes their nominated provider then essentially other healthcare providers can 'obtain' another providers information and take 'ownership' of that information. What rights does the initial provider have to ensure their information is maintained?
- liability for privacy breaches – practitioners and practices are fearful of becoming involved because of the significant fines and penalties for privacy breaches together with the fact that professional indemnity policies do not generally cover fines and penalties
- whether a practitioner is required to obtain consent from a patient every time they access the PCEHR or upload or download documents
- Practitioners are reluctant to participate as they are concerned they may be exposed to risk, their medico- legal liability and the security and reliability of the clinical information. [66]The basis for medical records has traditionally been that the provider of the medical services [66]controls the content.
- The medico-legal risk for medical practitioners is further increased in circumstances where the consumer can set access controls.
- All pathology reports should be sent, as incomplete result sets are not useful to the clinicians and may put patient safety at risk.
- The current PCEHR has multiple safety risks including:
 - Using administrative data (e.g. PBS data and Prescribe /Dispense information) for clinical purposes (ascertaining current medications) – a use never intended;
 - Using clinical documents (discharge summaries) instead of fine- grained patient data e.g. allergies. Ensuring data integrity is often not possible within documents (e.g. identifying contradicting, missing or out of date data);
 - Together the secreatean electronic form of a hybrid record with no unitary view of the clinical 'truth'. Hybrid records can lead to clinical error by impeding data search or by triggering incorrect decisions based on a partial view of the record
 - Shifting the onus for data integrity to a custodian GP avoids the PCEHR operator taking responsibility for data quality (a barrier to GP engagement and a risk because integrity requires sophisticated, often automated checking).
 - No national processor standards to ensure that clinical software and updates (and indeed the PCEHR) are clinically safe.
- A major lesson from patient safety is that open disclosure is essential to ensure patient and clinician trust in a system, and to maximize dissemination of lessons learned.

GPs have concerns about privacy and confidentiality of the patient data that they upload to the PCEHR. It is unclear to GPs who may have access to the data that they upload and what their medico-legal liability might be if it is accessed inappropriately. They also have concerns about their medico-legal liability if other health-care professionals rely on information that they have uploaded, particularly if the patient has requested that significant items, for example Hepatitis B or HIV status, be withheld.

Quote - BPS



16. Marketing

- Evidence of how PCEHR is having a positive impact on delivery of care
- Lack of compelling and timely communications on the relevance and value of the PCEHR to the clinicians and their businesses
- Promote benefits of eHealth not just PCEHR
- Scare journalism creates unease in the profession, whilst positive stories receive little publicity.
- Many patients lack confidence in the system.
- There needs to be more information in the community to create trust in the system.
- The current title sets an expectation that the PCEHR is a patient tool only, not one that that supports and fosters the patient/health practitioner relationship.
- Public education and awareness strategies required to emphasise to the Australian health consumer the value and benefits of an electronic health record.
- As the most frequently visited health care destination, community pharmacies should be used to promote the benefits of electronic health records to consumers
- Very few consumers (like clinicians) are actually aware of the potential benefits for the PCEHR.
- Clinician input is also essential in designing the **marketing** of the system so that a customer orientation is taken in all marketing material. Whilst patients may be considered the ultimate customer, clinicians are an essential 'intermediate' customer and their needs must be taken into account in designing any marketing campaigns.
- General practice has not been well informed about the benefits of the PCEHR to their patients or to themselves.
- Medicare Locals are engaging with consumer groups and general community to increase their awareness of eHealth and more generally improve their health literacy.
- Poor penetration of understanding of the PCEHR throughout rural and remote Australia
- As the health consumer's most accessed health destination, pharmacies can play a pivotal role in advocating and facilitating consumer uptake of the PCEHR
- Implement an intensive mainstream media national consumer awareness campaign.



Addendum 4

Announcement of the Review of the PCEHR including terms of reference.

THE HON PETER DUTTON MP MINISTER FOR HEALTH MINISTER FOR SPORT

3 November 2013 – MEDIA RELEASE

Federal Government to review electronic health records

Federal Health Minister, the Hon Peter Dutton, today announced a review of Australia's struggling Personally Controlled Electronic Health Records program which has failed to attract enough doctors to participate in the project.

"While the previous Coalition government laid the foundations for ehealth by getting computers into doctors' practices, Labor comprehensively messed up the next stage and has wasted over a billion dollars in its failed attempt at the second phase - moving to personal electronic health records".

Mr Dutton said a year after the introduction of the electronic health records system only a fraction of Australians have established a record and for those who have, only a few hundred doctors have added a Shared Health Summary..

"This defeats the purpose of having a national, electronic system that is meant to help save lives.

"The government fully supports the concept of electronic health records but it must be fit for purpose and cost effective.

"I am therefore announcing today a review of ehealth records to be chaired by Richard Royle, Executive Director of the UnitingCare Health group in Queensland.

"Mr Royle holds a Bachelor of Arts and Masters of Health Administration degrees, and is an active member of the Executive Team responsible for all of UnitingCare's services in Queensland, including Bluecare and UnitingCare Community, as well as UnitingCare Health.

"In addition, Mr Royle is Vice-President of the Australian Private Hospitals Association and he brings more than 30 years experience in management of public and private health services to the position of Review Chair. He is also overseeing the implementation of Australia's first fully integrated digital hospital in a pilot project at Hervey Bay in Queensland."

Mr Dutton said Mr Royle will be assisted in the Review by Dr Steve Hambleton, president of the Australian Medical Association and Andrew Walduck, Chief Information Officer of Australia Post.

"The Review team's expertise encompasses information technology, patient and medical services and business administration which I believe is the right mix to put the electronic health records program back on track."

The Review panel will invite submissions from the public along with key stakeholder groups including peak clinical bodies.

The Review will report back to Minister Dutton by mid-December 2013 after which the government will consider the recommendations and respond.

Media contact: Kay McNiece, Minister Dutton's Office, 0412 132 58 Review Terms of Reference

The panel will conduct a Review into the personally controlled electronic health record system dealing with implementation, uptake and including, but not limited to the following:

- The gaps between the expectations of users and what has been delivered
- The level of consultation with end users during the development phase
- The level of use of the PCEHR by health care professions in clinical settings
- Barriers to increasing usage in clinical settings
- Key clinician and patient usability issues
- Work that is still required including new functions that improve the value proposition for clinicians and patients
- Drivers and incentives to increase usage for both industry and health care professionals
- The applicability and potential integration of comparable private sector products
- The future role of the private sector in providing solutions
- The policy settings required to generate private sector solutions
- The Panel will make findings and recommendations to the Minister.

eHealth Records in Hong Kong

John Bacon-Shone, SSRC, HKU

Background

Around the world, developed countries are working towards the ideal of eHealth records (eHR for short), i.e. your medical records shared securely with all your healthcare providers, in order to improve quality of medical care and reduce the number of unnecessary medical tests. However, there are significant difficulties, both in managing the development of such a complex IT system and also in balancing privacy rights against medical needs.

Hong Kong is very well placed to be a leader in this area because of the large role that public hospitals (the Hospital Authority or HA) play in providing emergency and chronic care and because they have already developed a large scale eHR system to serve the needs of all the public hospitals and clinics.

However, the findings of the PCPD audit of an HA hospital in 2008, presentations from the eHR team and The Legal, Privacy and Security Framework for Electronic Health Record Sharing □ Public Consultation Document issued last year¹, provide grounds for concern about whether the current balance of privacy and medical needs is appropriate.

The three major issues for discussion relate to the proposals in the consultation document for the handling of personal identifiers, control of what data is shared and legislative controls.

1. Personal Identifiers

The HA audit made clear that the HA continued to use ID card numbers as personal identifiers almost everywhere, even where it is clearly not necessary and could be replaced by more privacy sensitive identifiers, could be encrypted or replaced by a hash. The HA was unable or unwilling to distinguish the needs of authentication from what is needed for linkage of personal data. It is unclear from the documents whether this has yet been fully understood. There also appears to be no recognition of the risk of giving access to medical data without direct identifiers, given that medical history will often provide an indirect identifier. These elements together mean that any security breach is likely to be catastrophic in allowing people to easily connect medical records to specific individuals.

2. Control of data sharing

From a privacy perspective, the starting point is that data subjects should have control of the use of their personal data, unless there are overwhelming considerations to the contrary. However, this principle is nowhere to be found in the consultation document, which seems instead to be based on the principle that doctors know best, regardless.

¹ downloaded May 20, 2012 from
http://www.ehealth.gov.hk/en/public_consultation/doc/full_consultation_document.pdf

There is also no reference to fair collection. From an ethical perspective, informed consent must be freely given without being blackmailed by being given choices that involve undue inducements or pressure. However, I believe the proposals in the document fail this test as they do not allow the patient ANY choice as to what data is shared, it is all or nothing.

The arguments in section 4.30 of the consultation document argue against any form of a safe deposit box to allow patients to exclude some medical data from normal sharing on the grounds that:

- 1) it would undermine the completeness of the eHR and the integrity of the eHR Sharing System and in turn affect the quality of healthcare;
- 2) healthcare providers would need to know whether the data in the safe deposit box is clinically relevant to treatment, or points to extra caution in handling the patients (e.g. in case of infectious disease). This necessitates the concurrent access to the eHR and the information in the safe deposit box every time;
- 3) it is practically difficult for healthcare professionals to determine which particular episodes can be regarded as sensitive health data to be stored separately in the safe deposit box. Apart from the names of illness/diseases, name of specialists, medications, etc. may all point to the health status of patients;
- 4) the feature would add an extra layer of complexity to the design of the eHR sharing infrastructure and in turn impose extra administrative costs, both for developing and operating the eHR Sharing System; and
- 5) there may also be a labelling effect on patients with a safe deposit box, since it is necessary to have their eHR flagged up.

These arguments are very weak and do not stand up to careful scrutiny:

- 1) it is not clear that completeness is essential
- 2) it should be clear for many treatments what medical data is essential
- 3) it should be for patients, not healthcare professionals to decide what is sensitive
- 4) additional cost can be justified, given the privacy rights
- 5) it should be for patients to choose whether they accept any labelling by healthcare professionals.

It is important to realize that the coverage of the existing system is extensive as it covers nearly all citizens and HA currently keeps all data since they started their internal eHR system (more than a decade) and I would assume that the Department of Health (DH) records also cover a long period.

The proposal here is all or nothing – so if a cancer patient wants their private cancer specialist to have access to his/her hospital data (as any reasonable person would), he/she must agree that the doctor has access to ALL medical history, including for example any visits to a clinic for sexually transmitted disease at any time since DH and HA records began! This is clearly a form of blackmail and completely fails the test of informed consent and fair collection. I fully understand the need to limit choice as to which data is placed in a safe deposit box, but it is totally unreasonable to

exclude this essential option completely. If a patient chooses to limit access to some of his medical data, there must be a very powerful life-saving argument for not allowing that choice, not simply convenience or assuming that doctors know best.

3. Legislative controls

The paper proposes new legislation, but does not make it explicit that this will not override the protections of the PDPO, but instead only add additional protections. Any removal of PDPO protections is unacceptable. For example, access to eHR data for research in non-anonymised form, clearly **MUST** be approved by the PCPD in addition to any research board setup by the bureau (which does not appear to include any privacy expertise). Evidence from the HA audit showed unwillingness to design the system to properly balance privacy against access for doctors or to ever reduce access rights for doctors, so it is essential for the PCPD to have ongoing oversight of the system.