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Toward better implementation: Australia's My Health Record

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Executive summary

A well implemented and fully utilised electronic health record system should strengthen a health system by improving quality and safety, ensuring continuity of care and improved health outcomes as well as reducing waste and inefficiency in the health system.

Australia chose to pursue a personally controlled electronic health record (PCEHR) system following a 2009 recommendation from the National Health and Hospital Reform Commission. A PCEHR is a special class of electronic personal health record where a consumer controls his or her record content and record access, which means only nominated health practitioners are able to access nominated information in the record.

Due to a lack of uptake and utilisation, in 2015 the Australian Government announced a system overhaul, which included rebranding the PCEHR to My Health Record and moving from an opt-in to an opt-out system. While the overhaul attempts to address the key problems identified in a 2013 external review of the PCEHR, a number of experts have flagged concerns with the new My Health Record, which should be addressed prior to implementation.

The following are three key and ongoing implementation concerns along with recommended actions to overcome these concerns.

Lack of registered users, system use and clinical utility

The following actions are recommended to accelerate achievement of My Health Record critical mass, system use and clinical utility:

- comprehensive system security and privacy safeguard review with subsequent action plan to address concerns prior to opt-out pilots, followed by proactive messaging to consumers and providers that technical security has been dealt with in the design of the record
- comprehensive communications and engagement strategy with targeted and sustained consumer- and provider-specific education and registration activities leveraging consumer groups, peak bodies, professional colleges and software distributors
- comprehensive and best-practice provider training based on an iterative process to develop training modules and the training platform with stakeholders
- registration incentives for both consumers and practitioners such as an increased Medicare rebate for system use as part of clinical activity
- technological and business support, including financial incentives to service providers nudging uptake and use
- software default settings linked into the interoperable national health record system
- flexible and clear policy and technical frameworks that are adaptable to clinical need

- structural change to the data sharing model where information necessary to the current treatment of a consumer is shared among the care team

Opt-in versus opt-out registration

The following actions are recommended to ensure a smooth transition from an opt-in to an opt-out consumer controlled electronic health record with evidence-based privacy and security protocols:

- comprehensive system security and privacy safeguard review of the current architecture evaluated against a repurposed opt-out functionality, which includes both threat and risk assessments as well as privacy impact assessments
- action plan stemming from the review to implement a mix of technology, policy and process mechanisms aimed at strengthening security and privacy controls—to be completed prior to My Health Record's opt-out trials
- public education campaign demonstrating system security and privacy safeguards
- engagement with software developers and distributors to ensure software compliance with necessary system changes and to ensure ongoing system interoperability
- update current provider training due to opt-out transition and work with the sector to develop and rollout revised modules

Governance

The following actions are recommended to ensure best practice and inclusive My Health Record governance arrangements:

- key national and regional stakeholders as well as consumers should be part of My Health Record's governance arrangements in order to secure buy-in from the health and community sectors and key consumer groups
- consideration should be given to the following building blocks for effective governance:
    - strong leadership, culture and communication
    - appropriate governance committee structures
    - clear accountability mechanisms
    - working effectively across organisational boundaries
    - comprehensive risk management and compliance systems
    - strategic planning, performance monitoring and evaluation
    - flexible and evolving principles-based systems
- the Council of Australian Governments' Standing Council on Health should play a leadership role to ensure these effective governance building blocks become more than aspirational

Introduction

Despite the Australian Government's substantial investment in the development and rollout of the Personally Controlled Electronic Health Record (PCEHR), the health sector and public have not embraced this significant e-health initiative. Just prior to its 2015–16 Budget, the Australian Government announced a system overhaul, which included rebranding the PCEHR to My Health Record. While the overhaul attempts to address a number of key problems identified in a 2013 external review of the PCEHR, a number of experts have flagged concerns with the new My Health Record, which should be addressed prior to implementation.

This issues brief first considers why the PCEHR system was selected and its potential value to the broader Australian health system. It then provides an overview of the PCEHR's activities, progress and governance as well as the PCEHR review and the government response that announced the rebranding to My Health Record.

The brief ends by considering three key and ongoing implementation concerns, which should be addressed in order to successfully implement a consumer controlled electronic health record. They are:

1. lack of registered users, system use and clinical utility
2. opt-in versus opt-out registration
3. governance

Choosing a personally controlled electronic health record

An electronic personal health record is an online collection of a patient's medical history in digital format, which includes information such as personal characteristics, diagnosed medical conditions, laboratory results, current and past medications and immunisation history. A PCEHR is a special class of electronic personal health record where a consumer controls his or her record content and record access, which means only nominated health practitioners are able to access nominated information in the record (McMahon 2013, p. 112).

Australia chose to pursue a PCEHR system following a 2009 recommendation from the National Health and Hospital Reform Commission, which recommended that as part of a transforming e-health agenda:

> The introduction of a person-controlled electronic health record for each Australian is one of the most important systemic opportunities to improve the quality and safety of healthcare, reduce waste and inefficiency, and improve continuity and health outcomes for patients. Giving people better access to their own health information through a person-controlled electronic health record is also essential to promoting consumer participation, and supporting self-management and informed decision-making (NHHRC 2009, p. 8).

The Australian Government responded in 2010 with AUD 467 million to deliver an opt-in PCEHR by 2012. Consumers would register for a PCEHR to manage and access their own healthcare information and to authorise selected health service providers to use their information to provide more effective and co-ordinated care (McMahon 2013, p. 116).

The need for a well-implemented and functioning system

Australia's universal healthcare system consistently ranks near the top when comparing key health indicators and costs (OECD 2014; Davis et al. 2014, p. 7), but challenges such as an ageing population and increased rates of chronic disease and comorbidities are increasing the cost of healthcare as a proportion of gross domestic product (GDP) and negatively impacting health indicators (McMahon 2013, p. 112). In looking at the Australian Institute of Health and Welfare's most recent health expenditure data, total 2013–14 health expenditure in constant prices was AUD 154.633 billion or 9.78 per cent of GDP, which is an increase from a decade earlier where total 2003–04 health expenditure in constant prices was AUD 94.932 billion or 8.53 per cent of GDP (AIHW n.d.). The Australian Government's 2015 Intergenerational Report estimates that between 2015 and 2055 the Australian Government spend on healthcare will increase by more than 135 per cent in today's prices (Treasury 2015, p. 60).

Greater consumer engagement, empowerment and partnership with healthcare providers are identified as key elements to strengthen and improve Australia's health system and indicators, as well as reduce costs. McMahon (2013) argues Australia's PCEHR is an opportunity to improve the quality and safety, to improve continuity and health outcomes for patients and to reduce waste and inefficiency in the health system (p. 112). A review of similar electronic personal health record systems in the United States and the United Kingdom support this assertion (Reeves et al. 2013, pp. 71–2). Australian consumers are generally supportive of the move toward greater engagement and control. In a 2014 study examining how Australians perceive the promoted idea of having a PCEHR, in a sample of 750 participants 34 per cent were interested and 33 per cent were very interested in managing their personal health (Andrews et al., p. 894).

A financial incentive also exists for a well-implemented and functioning system. On 10 May 2015, when announcing the PCEHR system overhaul and rebranding to My Health Record, federal Minister for Health Sussan Ley stated 'a fully-functioning national e-health system could save taxpayers [AUD] 2.5 billion per year within a decade by reducing inefficiencies, with an additional [AUD] 1.6 billion in annual savings also delivered to the states' (Ley 2015b). In a 2010 report by consultancy Booz & Company, it estimated that fully digitising the healthcare sector would realise AUD 7.6 billion in annual savings by 2020 and that this figure only reflects direct savings and does not include savings through economic flow-on effect (Booz & Company 2010, p. 2).

Personally Controlled Electronic Health Record overview

The Australian Government Department of Health's most recent PCEHR System Operator Annual Report provides an overview of the system's activities, progress and governance.

The PCEHR System Operator is the Secretary of the Department of Health who works with various agencies to deliver the PCEHR (Health 2014, p. 5).

On 1 July 2012, the PCEHR began to provide a 'secure, national infrastructure to support a shared electronic health record which can be viewed by patients and their authorised healthcare providers' that is consumer controlled and accessible online anywhere in the world. By 30 June 2014, 1,729,846 individuals registered for a PCEHR, of which 59.3 per cent were assisted to register by a health service provider with the remainder registering online, by phone, mail or face-to-face. Registered, participating health service providers, such as general practice, hospitals, aged care, dental, physiotherapy and pharmacy, reached 7,233 people over this period (p. 3).

Software manufacturers and distributors are important to the PCEHR system as they provide the software used by health service providers to access and update PCEHRs. Specific software is able to access the PCEHR system after completing a compliance and accreditation process (p. 16).

The Personally Controlled Electronic Health Records Act 2012 commenced on 29 June 2012 and provides the legal framework for the PCEHR system (p. 5). Operated by the Australian Government Department of Human Services, the Healthcare Identifiers Service maintains a national system for uniquely identifying individuals and healthcare service providers, which is governed by the Healthcare Identifiers Act 2010 (p. 6).

External review, recommendations and government response

Following a change in federal government, then-federal Minister for Health Peter Dutton commissioned an external review into the implementation and uptake of the PCEHR by a panel of health and information technology experts on 3 November 2013, which was completed by December 2013 and publicly released on 19 May 2014 (Health 2014, p. 3; Royle et al. 2013, p. 5). Commenting on the release of the external review and its 38 recommendations, Dutton said the review 'provided crucial advice on how the PCEHR could be improved', and it 'found strong support for continuing to develop and implement a consistent and effective electronic health record for all Australians'. However, Dutton concluded 'many of the existing problems with the PCEHR system stem from the rushed early implementation' (Dutton 2014).

Led by Richard Royle, Executive Director of the UnitingCare Health Group in Queensland, the expert panel included Dr Steve Hambleton, then-President of the Australian Medical Association, and Andrew Walduck, then-Chief Information Officer of Australia Post (Royle et al. 2013, p. 12). The Australian Government Department of Health along with 86 organisations and associations provided submissions within a two-week timeframe, and individual interviews were conducted with health and information technology experts (pp. 3–4). The review identified 14 common concerns and made 38 recommendations (pp. 14–8), which are listed in appendix 1.

The expert panel stated that ‘overwhelming support was found for continuing the path of implementing a consistent electronic health record for all Australians’ (p. 13), and found that ‘an electronic health record remains a critical part of the future health infrastructure for Australia’ (p. 12). The expert panel added ‘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 the broader system of healthcare’ (Royle et al. 2013, p. 13).

The Australian Government’s 2014–15 Budget allocated AUD 140.6 million to support e-health and the PCEHR system as it prepared its response to the recommendations. (Dutton 2014)

On 10 May 2015, federal Minister for Health Sussan Ley announced a AUD 485 million ‘rescue package’ from the Australian Government to redevelop the PCEHR system through a rebranded My Health Record system with a trial opt-out, rather than opt-in, option (Ley 2015b). Two days later, the Australian Government delivered its 2015–16 Budget, which stated the following in the Budget papers:

> The Australian Government is committed to a national shared electronic health record system. In response to the Review of the Personally Controlled Electronic Health Record (PCEHR), the Government will redevelop the system to improve its usability and clinical utility, strengthen eHealth governance and operations, and trial new participation arrangements. The PCEHR will be renamed My Health Record and the Australian Commission for eHealth will be established to manage governance, operation and ongoing delivery for eHealth from 1 July 2016” (Australian Government 2015, p. 113).

Introduced and read a first time to the House of Representatives on 17 September 2015, the Health Legislation Amendment (eHealth) Bill 2015 proposes to amend a number of acts to rebrand PCEHR to My Health Record, to trial opt-out arrangements in selected regions and enable opt-out to occur nationally if the trials are successful and to make a number of technical, administrative and structural changes to support the transition to My Health Record (Parliament of Australia n.d.).

While the Australian Government works toward addressing the concerns and recommendations outlined in the external expert panel review, three key and ongoing implementation concerns have been flagged by experts, which should be addressed in order to successfully implement a national consumer controlled electronic health record that will assist in improving population health outcomes and reducing health expenditure. Considered below, they are:

1. lack of registered users, system use and clinical utility
2. opt-in versus opt-out registration
3. governance

Lack of registered users, system use and clinical utility

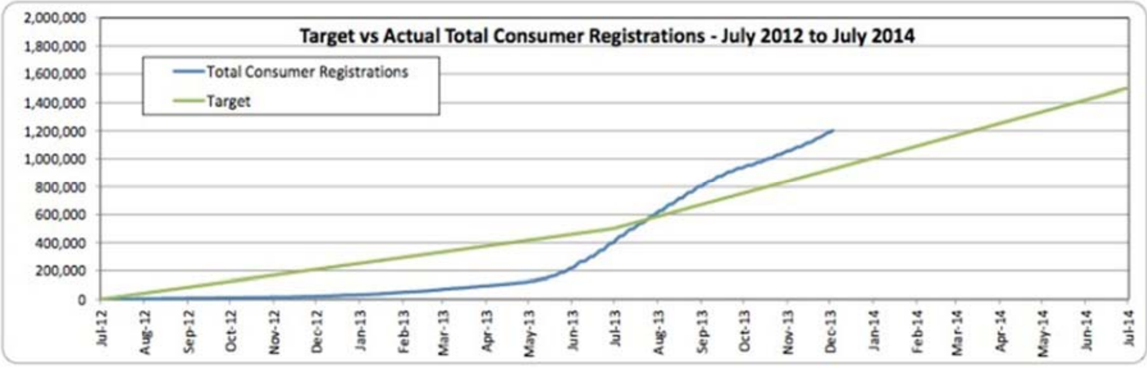
When announcing the redevelopment of the PCEHR to My Health Record, Minister Ley stated less than one in ten Australians were registered to the PCEHR system (Ley 2015b). Does this statistic represent implementation failure after two years and 10 months of system operation?

McMahon (2013) outlines how implementation was to focus initially on registering individuals who interact with the healthcare system most frequently such as people with chronic conditions and comorbidities, seniors, Aboriginal and Torres Strait Islander peoples, and mothers and infants (p. 116). And to encourage healthcare provider registration, an implementation strategy identified working with software vendors to ensure software availability, supporting professional colleges to drive uptake in their professions and using incentives to encourage participation (p. 125).

Recent surveys indicate the strategy did not work in raising awareness and use. A national cross-sectional survey of 405 healthcare consumers and providers found that they had relatively low PCEHR awareness and knowledge with only 9 per cent identifying as having some knowledge (Lehnbom et al. 2014, pp. 406–7). In a separate survey of 750 participants, 67 per cent stated they were not aware of the PCEHR, 84 per cent stated they did not receive any information about the PCEHR from online sources they use, and 96 per cent stated they had not been approached by their medical practitioner to opt-in and register with the system (Andrews et al. 2014, p. 894).

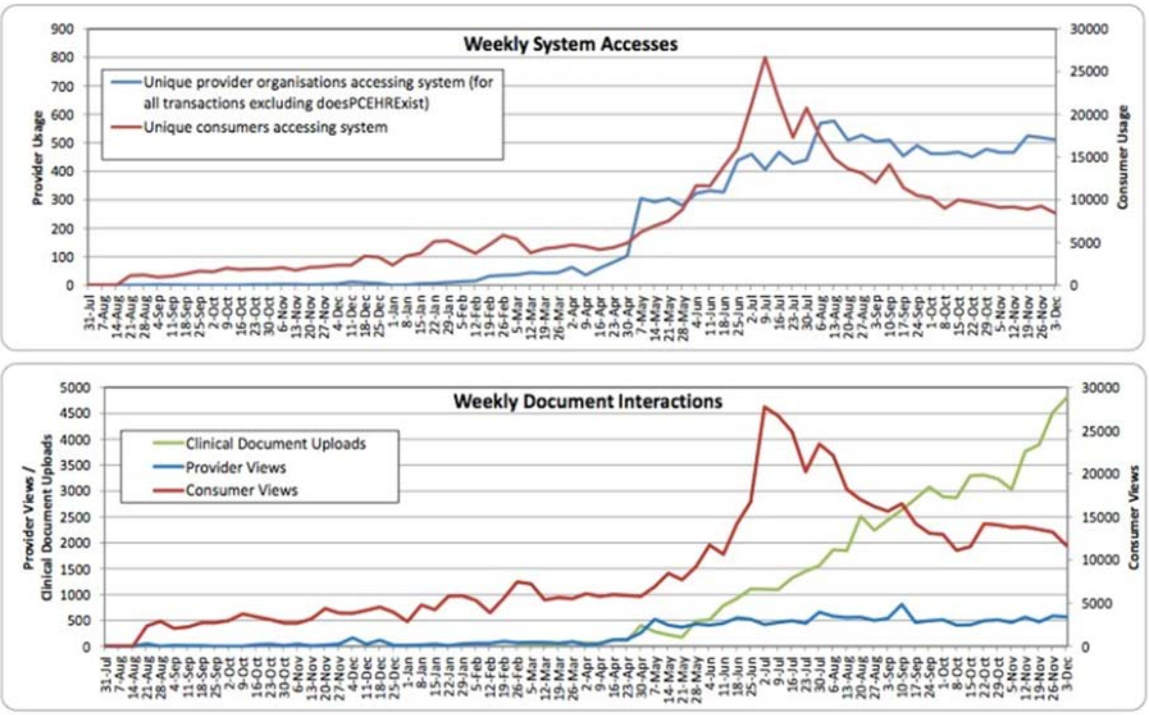
When the expert review panel examined the PCEHR registration target against total consumer registrations from July 2012 to December 2013 (figure 1) it noted that a registration spike only occurred during a deliberate registration drive prior to the 2013 federal election (Royle et al. 2013, p. 6). It was also noted that consumer access to the system dropped rapidly and provider access stayed flat even with clinical content added to the system (figure 2). It was suggested this was likely the result of poor usability and clinical value (p. 6).

Figure 1: PCEHR target vs total consumer registrations Jul 2012 to Dec 2013



Source: Royle et al. 2013, p. 6

Figure 2: PCEHR weekly system accesses vs weekly document interactions Jul 2012 to Dec 2013



Source: Royle et al. 2013, p. 6

The Australian Government now seeks to solve this issue by piloting and eventually transitioning to an opt-out My Health Record. The communiqué for the 7 August 2015 Council of Australian Governments (COAG) Health Council stated that federal, state and territory Health Ministers discussed proposed legislative changes to implement opt-out trials in some states and territories and 'Ministers were invited to nominate trial sites' (COAG Health Council 2015).

While moving toward an opt-out system might ensure all Australian residents entitled to Medicare might eventually be registered with My Health Record, it does not guarantee consumer or practitioner utilisation in a meaningful manner. To overcome this, the literature, experts and the Northern Territory's My eHealth Record (MyEHR) provide lessons on how best to achieve both significant registration and use by consumers and practitioners, which would lead to quality improvements in clinical care, better health outcomes and reduced cost.

Coiera (2013b) outlines the literature's repeated call for ongoing stakeholder engagement leading toward culture change supported by user training to ensure successful electronic health record rollout and use (p. 178). Lehnbom, Brien and McLachlan (2013) posit that incentivising health service providers and also providing them with the information needed to successfully encourage consumer registration would help drive registration and use (p. 408). Coiera (2013b) makes the argument that the failure to provide adequate workforce training, despite the substantial sums spent on systems development and rollout, is a key cause of failure (p. 178).

In addition to workforce training, the record must be meaningful and safe from a clinical perspective. When announcing the redevelopment of the PCEHR into My Health Record, Minister Ley stated a functional national electronic health record system would ensure health service providers across Australia 'had instant access to the information needed to treat patients safely and efficiently without having to gamble on unknowns in their medical history' (Ley 2015b). However, Glance (2015) argues the redeveloped system does not guarantee providers will participate and supply needed clinical data nor does it guarantee consumers will grant access to treating service providers. Coiera (2013a) argues there is 'extensive clinical risk' inherent in this continued approach. And Glance (2015) points to the Australian Medical Association's guidelines that indicate 'a doctor cannot rely on the personal record to make clinical decisions'. While the default function will be for consumer data to be added to the national system, patients will still have the option to opt-out and disable data sharing with practitioners (Wilson 2015). Experts are adamant that only 'a fully distributed and shareable clinical record' is the appropriate course of action where 'all practitioners involved in the care of the patient would have access to the record or could obtain appropriate access when necessary' (Glance 2015). However, Wilson (2015) argues the current system's 'security and privacy safeguards are not up to scratch' and do not instil the needed consumer confidence to halt consumers opting-out of My Health Record.

In an evaluation of the Northern Territory's successful MyEHR provided to the 7 August COAG Health Council, Burger and Ingersoll (2015) outline a way forward to increase consumer and practitioner registration and use. MyEHR is not consumer-centric, and all health practitioners, not just general practitioners, control the system—that is, MyEHR is a more collaborative system inclusive of both consumers and health service providers. MyEHR took five and a half years to reach critical mass, which occurred when approximately 50 per cent of Northern Territory Aboriginal and Torres Strait peoples were registered. After this point the service became embedded into routine clinical and administrative workflow, there was an upsurge in adding and viewing clinical content and the system spread rapidly in prominence (pp. 5–6). While the evaluation stated 'there were no silver bullets which triggered immediate and sustained increases', it concludes that 'critical mass was achieved through sustained effort, continual reinforcement and iterative policy and system enhancements' (p. 6).

In light of recent literature, commentary and expert opinion, recommended actions to accelerate achievement of My Health Record critical mass, system use and clinical utility include:

- comprehensive system security and privacy safeguard review with a subsequent action plan to address concerns prior to opt-out pilots, followed by proactive messaging to consumers and providers that technical security has been dealt with in the design of the record

- comprehensive communications and engagement strategy with targeted and sustained consumer and provider-specific education and registration activities leveraging consumer groups, peak bodies, professional colleges and software distributors
- comprehensive and best-practice provider training based on an iterative process to develop training modules and a training platform with stakeholders
- registration incentives for both consumers and practitioners such as an increased Medicare rebate for system use as part of clinical activity
- technological and business support, including financial incentives to service providers nudging uptake and use
- software default settings linked into the interoperable national health record system
- flexible and clear policy and technical frameworks that are adaptable to clinical need
- structural change to the data sharing model where information necessary to the current treatment of a consumer is shared among the care team

All actions should be reviewed, endorsed and evaluated through the COAG Health Council. Ministers for Health should ensure their respective legislative frameworks are updated to align with these changes within a reasonable and agreed upon timeline. Federal, state and territory governments should task Primary Health Networks to drive uptake by both consumers and providers, with this being a requirement to receive funding and support. Local Health Districts should be required to implement the system for use by their clinicians and staff. Pooled funding should support all training and outreach activities.

Opt-in versus opt-out registration

The Australian Government agreed with the expert panel that a key challenge is the opt-in nature of the PCEHR system. Minister Ley stated service providers are more likely to use the system if all patients have a record, which is why the government will trial an opt-out model (Ley 2015b). On 28 October 2015, Minister Ley announced Far North Queensland and the New South Wales Nepean Blue Mountains region as opt-in trial sites to commence in early 2016 encompassing around one million people (Ley 2015a).

The Australian Healthcare and Hospitals Association (AHHA 2015) and the Australian Medical Association (Jolly 2015) are supportive of the move in principle. The Consumer Health Forum stated active leadership, an open and transparent process and education for both consumers and practitioners are vital for a successful transition, and the Royal Australian College of General Practitioners has called for an evidence-based system transition with trial sites practitioner-directed and not directed by ‘bureaucrats’ (Jolly 2015).

Any move toward an opt-out system will also need to address low levels of public support. When surveyed, only 27 per cent of healthcare consumers and providers agreed or strongly agreed a consumer controlled electronic health record should be compulsory (Lehnbom et al. 2014, p. 407).

Wilson (2015) argues the system's consent model cannot be inverted 'as if it's a switch in the software' stating that the redeveloped My Health Record's security must 'be demonstrably better' and 'properly built in, not retrofitted'. Wilson points to the most recent PCEHR privacy impact assessment, which 'makes it clear that opt-in participation is core to the existing architecture'. Wilson concludes that as the current system's privacy and security architecture was never designed for opt-out, that such a switch without a fundamental system review and redesign 'would be an amazing breach of the public's trust in the healthcare system'.

In light of recent literature, commentary and expert opinion, recommended actions to ensure a smooth transition from an opt-in to an opt-out consumer controlled electronic health record with evidence-based privacy and security protocols include:

- comprehensive system security and privacy safeguard review of the current architecture evaluated against a repurposed opt-out functionality, which includes both threat and risk assessments as well as privacy impact assessments
- action plan stemming from the review to implement a mix of technology, policy and process mechanisms aimed at strengthening security and privacy controls—to be completed prior to My Health Record's opt-out trials
- public education campaign demonstrating system security and privacy safeguards
- engagement with software developers and distributor to ensure software compliance with necessary system changes and to ensure ongoing system interoperability
- update current provider training due to opt-out transition and work with the sector to develop and rollout revised modules

All actions should be reviewed, endorsed and evaluated through the COAG Health Council. The Australian Government Department of Health should lead these actions with a view to transitioning this work to the yet to be created Australian Commission for eHealth. Ministers for Health should ensure their respective legislative frameworks are updated to align with these changes within a reasonable and agreed upon timeline.

Governance

The expert panel identified inadequate governance arrangements as a key concern. The Australian Government's 2015–16 Budget attempts to strengthen governance arrangements for the My Health Record (Australian Government 2015, p. 113) from what Minister Ley characterised as an 'overly complicated and bureaucratic' system under the PCEHR (Ley 2015b). Operations and associated governance arrangements will transition from the Australian Government Department of Health to a new Australian Commission for eHealth from July 2016, and a transition taskforce will be established to manage this transition (McDonald 2015). Health policy functions, however, will remain within the Department of Health (Ley 2015b). Established as a new corporate Commonwealth entity through the Public Governance, Public Accountability Act 2013, the new Commission will also assume responsibility of the broader e-health system currently managed by the National E-Health

Transition Authority, which will cease operation once the Commission assumes full operational control (McDonald 2015).

Minister Ley has stated all jurisdictions have agreed to this approach (Ley 2015b), and the COAG Health Council continues to work toward the transition to My Health Record (COAG Health Council 2015).

The Australian Public Service Commission (2007) has stated that ‘governance can only work if it is part and parcel of the culture of the organisation’ (p. iii). While the Australian Government works toward improved My Health Record governance arrangements, consideration should be given to the following ‘building blocks for effective governance’ (pp. 5-19), which should be purposefully built into the development of, and transition to, the new Australian Commission for eHealth:

- strong leadership, culture and communication
- appropriate governance committee structures
- clear accountability mechanisms
- working effectively across organisational boundaries comprehensive risk management and compliance systems
- strategic planning, performance monitoring and evaluation
- flexible and evolving principles-based systems

Additionally, the transition taskforce and the new Commission should invite key national and regional stakeholders as well as consumers to be part of its governance arrangements in order to secure buy-in from the health and community sectors and key consumer groups.

The COAG Health Council should play a leadership role to ensure these effective governance building blocks become more than aspirational—they should become lived experience during the current transitional period for Australia’s consumer controlled electronic health record. For My Health Record, and e-health more broadly, to realise their full potential, these governance building blocks must become culturally embedded within the transition taskforce and the Australian Commission for eHealth.

Conclusion

The Australian Government has invested heavily into the development and rollout of its consumer controlled electronic health record system—first in the PCEHR and now in the transition to My Health Record. A well implemented and functioning system has the ability to improve the quality and safety of healthcare, reduce waste and inefficiency, and improve continuity and health outcomes for patients, all of which would benefit a health system currently under financial strain and facing an ageing population with increasing rates of chronic disease and comorbidities.

Australia’s approach to electronic personal health records attempts to empower health consumers through an interoperable system based on national standards and goals, and the

Australian public is supportive of such an approach. However the PCEHR faced a number of key challenges, which the transition to My Health Record attempts to overcome.

In order to realise its full potential, Australian governments and Ministers for Health should pay special attention to three key and ongoing implementation concerns, which are:

1. lack of registered users, system use and clinical utility
2. opt-in versus opt-out registration
3. governance

This issues brief has recommended actions the Australian Government and the COAG Health Council should pursue in order to successfully implement a repurposed consumer controlled electronic health record that has the potential to lead to improved population health outcomes and reduced health expenditure.

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Appendix

Royle Review: 14 common concerns and 38 key actions

The Royle Review's 14 common concerns (p. 14):

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.

The Royle Review recommended 38 key actions to realise the benefits of the PCEHR (pp. 15–8):

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:

1. Demographics
2. Current Medications and Adverse Events
3. Discharge summaries
4. 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.