RACGP

RACGP Submission

Review of the Personally Controlled Electronic Health Record (PCEHR)

22 November 2013

The Royal Australian College of General Practitioners

About the RACGP

The Royal Australian College of General Practitioners (RACGP) is Australia's largest professional general practice organisation representing over 24, 000 urban and rural members. The College sets and maintains the standards for quality clinical practice, education and training and research in Australian general practice.

The RACGP has a strong history of being at the forefront of innovations in the health sector and is ideally placed to guide governments and other stakeholders to ensure they are informed of what is reasonable, workable and useful for general practitioners in Australia when implementing new eHealth initiatives.

The RACGP promotes eHealth as an enabler that supports the delivery of better patient outcomes. It has the potential and ability to improve practice efficiency, better support patient management, improve timely communication, gather and organise information and better use information to support safe and high quality care.

Executive summary

The RACGP supports a national shared electronic health record system and the clinical benefits of healthcare providers accessing healthcare information not available via normal communications.

The RACGP has a strong history of being at the forefront of innovations in eHealth and is supported by key general practice leaders in this field. The RACGP is therefore ideally placed to guide governments and other stakeholders on what is reasonable, workable and useful for general practitioners in Australia and provide resources and education to support this.

The RACGP's submission consists of two parts:

1. Part A – recommendations to address the key issues and re-focus on the successful delivery of core foundation services
2. Part B – provides specific commentary on the review's Terms of Reference

The RACGP strongly supports the adoption of 10 key recommendations:

1. Suspension of the current PCEHR development program.
2. Consolidation of existing PCEHR functionality, especially the Shared Health Summary.
3. Direct access to the web-based provider portal views via GP clinical desktop software.
4. An ongoing work program focusing on core foundation services.
5. Universally available, interoperable secure message delivery.
6. A transparent product development life cycle, with the RACGP as a priority stakeholder.
7. Clinically useful and safe eHealth products that align with clinical systems and workflow.
8. Strong, streamlined and transparent governance overseen by a single entity responsible that is accountable for all eHealth product design and release.
9. Clinician-developed and led education and training that is supported and delivered to general practice by the RACGP.
10. Development of a value and benefits business case to support continued general practice participation in the PCEHR.

General practice, through the RACGP needs to be an integral part of this process.

Part A: RACGP 10 key recommendations

1. Suspension of the current PCEHR development program.

The current PCEHR development program has resulted in the delivery of a product that is overly complex with a poor interface between local GP clinical information systems and the PCEHR system. The development program has been driven politically and by a desire for volume rather than high-quality, useful clinical information. The clinical community has not been effectively engaged in product development, especially with the current release program. This has resulted in a system that fails to meet clinical requirements, is not acceptable nor sustainable.

The PCEHR development program must now focus on meaningful clinical engagement that ensures delivering improved access to a clinically usable shared health summary that drives real benefits for the wider community through the sharing of information.

Immediate suspension of the current PCEHR development process, which includes advance care directives, pathology and diagnostic imaging results and the child eHealth record, will allow for consolidation of existing products and a review of the clinical benefit, usability, safety and provenance of clinical information being posted to the PCEHR.

The national action, as noted in the eHealth Strategy 2008, was to enable clinical information to flow seamlessly, be accessible and be shared across the Australian healthcare system. The current PCEHR development program has moved away from these core principles which stipulate that clinical information must be clinically curated. This ensures that healthcare providers, not normally involved in a patient's regular care, are not exposed to any additional duty of care or medico - legal risk.

For example, the proposed model for scanning Advance Care Directives (ACD) into the PCEHR is inadequate in that there has been no needs assessment undertaken and no provision for clinical curation or quality assurance controls. As a result, it remains uncertain from a legal perspective, as to whether a healthcare provider can be responsive to instructions from a scanned document. The clinical benefit for providers or consumers accessing a scanned ACD (as opposed to the provision of the location of the document) is unclear.

A further example is the Child eHealth Record allowing clinical information to be entered via the consumer portal with no clinical controls. As per the ACD, there was no formal needs assessment, no provision for quality assurance controls and no medico-legal or clinical safety risk assessments.

2. Consolidation of existing PCEHR functionality, especially the Shared Health Summary.

The RACGP strongly supports the shared health summary, however it believes that significant work is required to fully integrate the creation and updating of a shared health summary into established clinical workflows. This should be one of the highest priorities for the PCEHR program.

A shared health summary is a fundamental healthcare document curated and created by the patient's usual primary care healthcare provider. 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.

These core elements were identified by clinicians in the original consultation process as essential to providing healthcare services to patients previously unknown to the provider. The shared health summary

is based on the GP health summary which is the core document for continuity of care and supports the RACGP's vision of a medical home. For more than 30 years, the RACGP has promoted the value of an up-to-date GP health summary.

Currently, shared health summaries do not interact with the patient's local electronic health record within GP desktop clinical information systems. Clinicians are unable to seamlessly transfer unchanged or changed information from a previous summary to a new one. If systems were able to interact, this would improve the clinical usability and the reliability of information in the PCEHR.

Further, there should be focus on targeting those consumers who will benefit most from a PCEHR, rather than the current focus on sheer numbers of consumer registrations.

3. Direct access to the web-based provider portal views via GP desktop software

There has been substantial investment of clinician time and resources in to the design of the Provider Portal. However, GPs access the PCEHR through their clinical GP desktop software. The views provided through the various vendor desktop systems are not standardised, safe or intuitive. The individual desktop systems each display different documents and are not searchable. This poses a clinical safety risk.

The RACGP has significant concerns about the integration of existing PCEHR functionality into GP desktop solutions. The RACGP is alarmed that there is significant disconnect between the agreed clinical specifications and the product solutions released by vendors, which will have substantial implications on workflow and clinical utility. From our consultation with the vendor community, it is the RACGP's view that these challenges are due to the lack of clinical involvement in the development of realistic project milestones and deliverables. A strong working relationship between software vendors and the RACGP to deliver a PCEHR product, which is clinically safe and can be integrated into current GP systems without major disruption, is crucial.

It is important to note that the investment of additional resources to enhance the existing software vendor view is not appropriate when there is already an established and accepted clinically suitable view - the provider portal view. This established view should be used.

4. An ongoing work program focusing on core foundation services.

The RACGP supports the original foundations of the eHealth work program defined by the National eHealth Strategy in 2008, which includes the Healthcare Identifiers (HI) Service, National Authentication Service for Health (NASH), standardised clinical terminologies and universally available interoperable secure message delivery.

The work program needs to re-focus on the continuity of core clinical documents (Shared Health Summary and Event Summary) and the point-to-point communication (Secure Message Delivery). These are the core functions of clinical value for GPs and other clinicians and provide the platform for engagement of the clinical community in the PCEHR.

Once these core foundation services are effectively embedded in practice, the PCEHR can then be extended.

5. Universally available, interoperable secure message delivery

Interoperable secure message delivery (SMD) will deliver better electronic communications between all healthcare providers and promote the creation of useful and shareable clinical documents. 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). Broader adoption of SMD between providers will result in a larger pool of electronic documents and clinical data which will inevitably flow into the PCEHR.

Secure message delivery needs to be a logical and interoperable process in order to be adopted by clinicians. At the moment, none of the vendor systems can exchange and use information. Currently, it is difficult to coordinate and manage the various digital certificates required to participate in the system. As a consequence, the central provider directory (HI HPD) is not adequately populated.

The RACGP notes that 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.

6. A transparent product development lifecycle, with the RACGP as a priority stakeholder.

Clinical engagement is essential to the end-to-end process of the product development lifecycle. Clinical input is required from the initial needs assessment, right through to the build, testing and implementation phases. Current fragmentation of the clinical engagement process has resulted in the end product not being fit-for-purpose.

Clinical engagement and testing through the product development lifecycle will improve the function and utility of the PCEHR. Technical solutions must be informed by clinical and business requirements. Proposed solutions require review and endorsement by clinical stakeholders. The RACGP is well placed to assist in the testing of technical solutions against the clinical scenarios.

7. Clinically useful and safe eHealth products that align with clinical systems and workflow.

The RACGP believes the development of functional requirements for GP desktop systems will allow vendors to develop products that are safe and useful for GPs, in line with a standards-based process.
Solutions must consider and align with both existing practice and clinical workflows to ensure that they are acceptable to providers, clinically meaningful, provide benefit and are clinically safe.

The interface between GP systems and other health information systems need to align with usual business processes and not impact on current workflow. The PCEHR in its current form represents a disruptive technology and, as a consequence, adoption by healthcare providers has proven to be problematic. The RACGP has the required experience to develop functional specifications and prioritise the functionality of eHealth and the PCEHR to assist in informing what is clinically useful and fit-for-purpose.

8. 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’.

The entity needs:

- meaningful clinical representation from the RACGP
- to be an independent authority, comprising representatives from all key stakeholders
- to be at arms’ length from the political and funding process.

9. Clinician-developed and led education and training that is supported and delivered to general practice by the RACGP.

The RACGP, with support from the Department of Health (DoH), assisted in the rollout of the PCEHR by providing peer-to-peer seminars from May - November 2013. The seminars reached approximately 3,000 practices and over 4,000 participants. The credibility and success of this program is attributed to the peer-to-peer model, where GPs spoke directly to GPs. The criticality of education and training for adopting the PCEHR was affirmed through this program, and demonstrated that general practice has a commitment to deliver best outcomes for their patients by sharing information electronically.

While the program was successful, it has not translated into meaningful use for a number of reasons including:

- Lack of targeted consumer registration and education
- Lack of a demonstration platform in which GPs can participate outside of the live environment
- Lack of maturity of the system (local software integration and commissioning).

10. The RACGP recommends development of a value and benefits business case to support continued general practice participation in the PCEHR

In the absence of a clear value and benefits business case, clinical adoption and meaningful use will not progress. There is no link between the existence of a PCEHR and improved service delivery and healthcare outcomes. GPs need to be provided with a clear PCEHR value proposition in terms of what will be delivered, including benefits and costs.

Part B: Specific commentary relating to the PCEHR review Terms of Reference

The RACGP provides specific comment in relation to the PCEHR terms of reference, including:

1. Your experience on the level of consultation with key stakeholders during the development phase
2. The level of use of the PCEHR by health care professions in clinical settings
3. Barriers to increasing usage in clinical settings
4. Comments on standards for Terminology, language and technology
5. Key clinician utility and usability issues
6. Key patient usability issues
7. Suggested improvements to accelerate adoption of the platform.

1. Your experience on the level of consultation with key stakeholders during the development phase

The RACGP believes that clinical consultation during the 'product development cycle' has not been meaningful and has resulted in less than ideal outcomes. This includes:

- A PCEHR system design that is over-engineered and represents a clear disconnect between the technical possibilities of the PCEHR and the potential realisation of clinical utility and safety. For example, the proposal that GPs would upload pathology and diagnostic imaging reports into the PCEHR, showed a lack of understanding of sector issues and applicability of the system at a global level. This would have been identified much earlier with clinical engagement.
- Conformance Compliance Accreditation (CCA) gateways which are not a substitute for either clinical safety assessment or clinical conformance processes.
- Lack of clinical involvement in the development of GP vendor panel processes, the milestones and the deliverables.
- The proposal that GPs would upload pathology and diagnostic imaging reports into the PCEHR showed a lack of understanding of sector issues. This would have been identified with earlier clinical engagement.

2. The level of use of the PCEHR by health care professions in clinical settings

Clinical adoption is low compared to consumer registrations, evidenced by:

- Only 1% of participants having a shared health summary uploaded (9,300 shared health summaries recorded for 1 million consumers registered).
- Less than 0.01% of prescribing and dispensing transactions have a corresponding record in the National Prescription and Dispense Repository (NPDR).
- Well-resourced eHealth sites that did not consider the dissemination of lessons and experience to significant stakeholders for evaluation and learning.

3. Barriers to increasing usage in clinical settings

The RACGP has identified a number of barriers to adoption of the PCEHR clinical settings, including:

1. Clinical risk issues
2. Difficulties registering and accessing the PCEHR system
3. A lack of value or business case for GPs to use the PCEHR.

Clinical risk issues:

- Clinical risks arising from multiple 'feeds' of clinical information without a trusted clinical gateway to ensure quality data and meaningful use.
- Accelerating a work program without the end-product being tested in a controlled demonstration environment prior to general release.
- Limited visibility and clarity around medico-legal and clinical safety issues that arise when eHealth design is in addition to current accepted clinical workflow.
- The Child eHealth Record has no interface through GP desktop clinical information systems, thus creating additional data quality, medico-legal and clinical safety risks, due to consumer entered information without clinical curation.
- Scanned ACDs into the PCEHR with no respect for the reflection, discussion and communication that enables a person to plan for their future medical treatment needs. Without clinical curation, the resultant document has little value for future periods of impaired decision-making capacity.

Difficulties registering or accessing the PCEHR system:

- Registering to participate in the eHealth record system is overly bureaucratic.
- The registration process is legalistic, with substantial legal and professional obligations applied to GPs and general practice business owners.
- Multiple certificates are currently required to access the PCEHR system. There must be one certificate that can be used within practices for user certification and authentication.
- Current business-to-business (B2B) views that are overly-complex, non-searchable, lack intuitive navigation and result in data over-load.
- The late release of vendor software, affecting implementation at the practice level.

A lack of value or business case for GPs to use the PCEHR

- Patient consenting arrangements shift substantial medico-legal risk to the GP.
- Limited visibility and clarity around clinical and medico-legal responsibility for contributing to a patient's PCEHR.
- No clear value or benefits for GPs to contribute to the PCEHR system.
- Lack of a demonstration environment to trial the use of the system rather than a 'live' environment.

4. Comments on standards for Terminology, language and technology

Standard terminology, language and technology are vital to the safe sharing of information. Recent decisions made without meaningful clinical engagement has resulted in terminology and standards that do not reflect clinical practice. This demonstrates a key disconnect between clinical need and the end product.

There is a need for better linkages between existing clinical systems and technologies and existing international and national technical specifications relevant to eHealth. The interconnection between an agreed GP reference set, SNOMED-CT and coding in GP clinical information systems, has not been established. This issue can be resolved with ongoing and meaningful clinical engagement.

5. Key clinician utility and usability issues

Key clinician utility and usability issues around the PCEHR, identified by the RACGP include:

- PCEHR views in GP clinical desktop systems are not consistent, searchable and pose a clinical safety risk.
- Shared Health Summaries do not interact with the patient's local electronic health record within GP desktop clinical information systems. Clinicians are unable to seamlessly transfer unchanged or changed information (data) from a previous summary to a new one.
- No overview document available through clinical desktop systems including MBS or PBS data.
- Large volumes of unreconciled and irreconcilable information pose risks of 'information overload' and the PCEHR being a 'data dump'. For example, the current National Prescribe and Dispense Repository.
- GPs need reliable access to a single help desk for all PCEHR issues.
- Need for assisted registration tool that is built into all GP clinical desktop systems.
- Functionality not working as intended. For example, private mobile phone numbers and email addresses were visible in the PCEHR, demonstrating the need to fully engage clinicians end- to- end, from development of the use case through to the integration of the specifications into a vendor solution.

6. Key patient usability issues

The key patient usability issues are around registration and education, including:

- Failure of consumers accessing and inputting information into their PCEHR, despite high registration rates.
- Poor consumer understanding regarding the value of the PCEHR in relation to their care.
- Lack of targeted consumer education or promotion of the benefits.
- Consent issues around the release of information to healthcare providers.

7. Suggested Improvements to accelerate adoption of the platform

The RACGP, as the peak body for general practitioners is well positioned to provide direct in-practice support and contribute to clinician - led and delivered education and awareness raising campaigns. However, the most critical requirement is an incentive or recognition for the additional infrastructure and effort required to participate in the PCEHR.

Adoption would also be increased with:

1. Clear clinical governance arrangements
2. Infrastructure that has been clinically tested
3. Improvements to clinical utility.

<u>Clear clinical governance arrangements</u>

- Governance by a single entity responsible and accountable for all eHealth product design and release.
- Product development cycle with meaningful clinical engagement to ensure that core functionality is achievable and sustainable.

Infrastructure that has been clinically tested

- A testing tool must be available at a practice level so that providers can test this and other PCEHR functionality on their desktops rather than experimenting in the real PCEHR.
- Software vendors need to work through a clinical governance model to ensure that:
    - all views to the PCEHR are standardised across all clinical information systems
    - there is an agreed standardised methodology for document creation in all clinical information systems
    - as a priority, they deliver point-to-point messaging through secure message delivery.
- Clinician-developed and led education and training that is supported and delivered to general practice by the RACGP.
- 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.

Improvements to clinical utility

- Provider portal view available via clinical desktop systems
- Single PKI authentication system for all of healthcare provider health and human services interactions
- Assisted registration tool should be built into all clinical desktop systems
- Encourage non-GP clinicians to use secure message delivery
- A single PCEHR help desk for clinicians
- The GPs Clinical Information System should be able to interrogate the PCEHR in the background to inform the clinician when there is a difference between the GP health Summary and the Shared Health Summary.