



RACGP

*Submission to the Department of Health
on the Electronic Health Records and
Healthcare Identifiers: Legislation
Discussion Paper*

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The Royal Australian College of General Practitioners

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About the RACGP

The RACGP is Australia's largest professional general practice organisation representing over 29,500 members working in or towards a career in general practice. The RACGP sets and maintains the standards for quality clinical practice and education and training 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 (GP) in Australia when implementing new e-health initiatives.

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

The RACGP has been an advocate for and supports a national shared electronic health record system and understands the clinical benefits of healthcare providers accessing healthcare information not available via normal communications. The RACGP supports the original foundations of the e-health work program, which includes the Healthcare Identifiers (HI) Service, National Authentication Service for Health (NASH), standardised clinical terminologies and universally available interoperable secure message delivery.

The RACGP welcomes the opportunity to provide comment on the electronic health records and healthcare identifiers legislation discussion paper. In the current environment where the Personally Controlled Electronic Health Record (PCEHR) still has many unresolved issues, the RACGP would like to provide both high-level feedback and specific feedback on the discussion paper.

Feedback on the discussion paper

The RACGP welcomes the commitment made by the Government in its 2015-16 budget to strengthen the national e-health system and support the continued development of the PCEHR. There are well identified issues with the current PCEHR model that require meaningful engagement between the Federal Government and the healthcare sector in order for these issues to be addressed effectively and for the PCEHR to be adopted. It is our view that the ongoing work program should focus on:

- the core clinical documents relevant to general practice (Shared Health Summary and Event Summary)
- medicines reconciliation, and
- point-to-point communication (interoperable Secure Message Delivery).

These are the core clinical value propositions for GPs and other clinicians and provide the platform for continuing engagement with the clinical community.

1. The PCEHR

There is ongoing confusion about the purpose of the PCEHR. A clear definition is required. The current definition in the paper that "*A PCEHR is an electronic summary of a person's key health information, assembled from information held by distributed participating organisations...*" does not correctly reflect what the PCEHR is. The PCEHR is, by its inherent design, a data and document repository that can provide

access to health information not normally available via other communication channels. From a general practice perspective, it is of most benefit in the context of the out-of-place and/or out-of-time patient.

A PCEHR enables an individual to view some of their own data and documents that have been made available through upload from clinical source systems by various health professionals and organisations. It enables the patient to allow other people, including health professionals who may be caring for them, to also view that information. The PCEHR by definition cannot necessarily provide a full clinical patient history or summary. The PCEHR may provide an individual easier access to more information than was previously available to them about their health status and healthcare. This in turn may enable the individual to become more actively involved in their own healthcare or provide more information to other health professionals (including in times of emergency).

However, simply having information uploaded to a person's PCEHR does not necessarily place the individual "*at the centre of their own healthcare*". An individual's understanding of their health is dependent on their health literacy and interest. There is wide variation in levels of health literacy and patients often require assistance from their usual GP and other health professionals to interpret the data in their PCEHR and to understand what it means for them. There is currently limited evidence available that supports the proposition that patients merely having access to their healthcare information leads to significant changes to healthcare outcomes.

2. *Healthcare Identifiers service (HI service)*

One of the current issues is data mismatches between the HI service and the data contained in clinical information systems preventing the download of HI numbers, which are required before providers can upload documents into the PCEHR.

This is an issue in the current opt-in context, which is manageable given the small number of patients who are PCEHR registered. However this becomes a much larger issue in an opt-out environment where the majority of patients are expected to have a record and practices are required to obtain an HI match in order to access a larger number of records.

The same matching rules that apply for successful return of a patient's Medicare number should be applied to the HI service. This would improve match rates and usability.

3. *Definitions*

3.1 Alignment between HI and PCEHR Acts

The term "*consumers*" is used in the PCEHR Act and "*healthcare recipients*" in the HI Act – both are defined to mean the same thing. If this terminology is to be aligned in both Acts and subordinate legislation, it should be taken into consideration that using the term "individual" may cause confusion with the Healthcare Provider Identifier-Individual (HPI-I).

3.2 Clarification of "healthcare"

The RACGP suggests that a mechanism be established to allow for recognised non-AHPRA registered providers, such as ambulance services, paramedics and dietitians, to be automatically allocated HPI-I numbers to eliminate the detailed application process currently required. These providers also need to be included in the wider education process to encourage their use of the PCEHR.

4. *Governance and ACeH*

The RACGP strongly supports the establishment of the Australian Commission for electronic Health (ACeH). However, the RACGP would like more clarity around the transition arrangements from the current governance, which should be expedited. This will ensure that confidence is rapidly built in the new commission. Governance of the PCEHR should be streamlined and transparent and overseen by ACeH, which should be responsible and accountable for the whole PCEHR system including any product design and release.

As GPs will be the main clinical users of this system, the RACGP should have representation on the board and within working groups/subcommittees. Clinical engagement with GPs is crucial to ensure usability and the RACGP is able to provide advice and represent the voice of general practice.

GPs are central to the success of the PCEHR. If GPs are to engage they need to be convinced of the use benefits for general practice. Education and awareness building activities will be important to achieve this. The education and training program delivered by the RACGP in 2013, which saw education through the provision of peer-to-peer seminars reach more than 3,000 practices and 4,000 participants, affirmed the critical role of education and training on the PCEHR. The initial education program focussed on raising awareness of the PCEHR and the ongoing usability issues were a barrier to increased adoption. The RACGP continues to have a strong commitment in supporting general practice to deliver the best patient outcomes via electronic sharing of information. Leveraging off previous work will ensure consistent education messages and provide efficiencies.

4.1 ACeH board

The RACGP supports broader e-health end-user representation in the governance of e-health. A clear and transparent process as to how these experts will be selected is required to ensure that relevant organisations and stakeholders are represented by people who are seen by the health professions as credible and authoritative. More clarity is required regarding the appointment of an “independent” chair for ACeH and its reporting structure. Clarity is also required regarding the reporting structure for ACeH in relation to both state and Commonwealth health ministers and the authority ACeH will hold under each jurisdiction.

5. *Opt-out issues and suggested model*

The RACGP has concerns about the mechanism of the new opt-out design. As this design removes the individual's choice, there is a need to ensure that people, and especially those who are socially disadvantaged and those with poor health literacy, are made aware of how to opt-out of the system. Clear information should be provided for carers and nominated and authorised representatives for those unable to make opt-out decisions for themselves.

The ability to opt-out needs to be accessible on multiple platforms e.g. online, via phone or in person. Patient education needs to include a greater focus on access controls and the ability for the patient to limit the number of providers who are able to view their record.

The RACGP supports the creation of a generic blank record and a trigger mechanism that is a positive choice by a patient to activate the record and allow health and Medicare information to populate the record. This might be initiated via a web-based portal, during a visit to a nominated provider GP or via a Medicare office. A nominated provider is the patient's regular GP where an ongoing relationship has been or will be established for the provision of healthcare services. The nominated provider will work together with the patient to determine the type of information to be shared and uploaded to the PCEHR. The role of the

nominated provider can currently be taken on by any GP and the RACGP recommends that this be aligned with the proposed medical home model and voluntary registration process. This will reinforce GP and patient relationships potentially leading to better quality Shared Health Summaries.

This would ensure that adequate safeguards and protections are in place for the patient. Having an opt-out system operating in parallel with the existing process poses significant risk. A proper privacy impact assessment should be conducted. It needs to be recognised that by not opting out patients provide standing consent for providers to post/upload information into the PCEHR.

A broad and informative education campaign is required for all participants in the trial areas. Education needs to be carefully developed and designed so that it can then be rolled out nationally when required. There needs to be strong support for the trial areas in terms of resolving issues for patients and healthcare providers and a transparent and responsive incident management framework should be established for the management and resolution of technical, safety and clinical issues.

The governance of the trials needs to be transparent and requires engagement from a wide range of stakeholders. Lessons learned from the trials should be captured and shared across all stakeholder groups through an open reporting process.

6. *Secondary use of information*

As the PCEHR is the patient's record, proper consent procedures should be in place for any use of the data in the PCEHR outside of individual patient care. When developing processes and systems around appropriate protection for preparation and disclosure of de-identified information, transparency, clarity and support (education) is required for both patients and clinicians.

7. *Participation agreement*

The RACGP agrees with the removal of the participation agreement and the transfer into legislation. However, thought needs to be given to how current participation agreements are terminated or transitioned, and how the responsibility be shifted to the individual and not solely the organisation.

Participants need an understanding as to what their obligations are in the proposed patient opt-out system. Participants will require access to the relevant legislation when signing up for an HPI-I so they fully understand their obligations when participating in the PCEHR system.

8. *Obligations to use PCEHR system*

The RACGP supports voluntary participation by healthcare providers and will not support any mandatory requirement for uploading of any documents by clinicians to the PCEHR (whether it is supported with a financial trigger or other mechanism).

Any requirement to mandate the uploading of certain or specific document types to the PCEHR via changes to the relevant acts and MBS requirements will almost certainly be significantly counterproductive and have a negative impact and will inevitably result in many Healthcare Provider Identifier – Organisations (HPI-O) and clinicians opting out of the process. This will not achieve any potential intended benefits for either the patient or the wider health system as a whole.

There is currently limited evidence available to indicate that the uploading of a document designed to provide customised patient care planning and guidance will have any benefit being uploaded to a national shared health record.

The RACGP supports additional incentives (such as an additional MBS item number for uploading a shared health summary) to promote and encourage uptake of uploading of documents into the PCEHR, with the emphasis that uploading should be optional and not mandatory. Provision of additional incentives should be in line with a workable and usable solution. As an example, uploading of specific documents is particularly useful for specific targeted patient populations (such as patients with multimorbidity) who will benefit from this.

9. The trials

When undertaking opt-out trials, these should be lead and advised by medical practitioners who have an understanding of the PCEHR system. The range of possible outcomes and associated deliverables for both patients and providers as part of an opt-out trial has to be clearly articulated and explained.

10. Collection, use and disclosure of information

The current legislation does not provide specific information regarding a GP's obligations to download information contained in the PCEHR so that it becomes part of a local clinical record. Also, given that patients currently control the information available, there may be additional medico-legal issues with regards to the liability where the provider has access to the patient's PCEHR but did not/could not find the information required.

11. Healthcare Provider Directory (HPD), etc.

The HI review has found that the opt-in basis of the HPD is a barrier to effective communications which adversely affect other e-health services that use the HPD, such as secure message delivery. The proposal is for the removal of the need for organisations to provide consent before they are listed in the HPD, i.e. organisations with an HPI-O would automatically be listed in the HPD. Individual healthcare providers would continue to be listed in the HPD only if they give consent. There should also be a mechanism whereby health provider organisations who do not want to be listed in the HPD should be given the opportunity to remove themselves from the directory (for example seed or network organisations that do not generate clinical communications and therefore do not need to be discovered).

12. Data removal from the PCEHR

There should be a streamlined, uncomplicated procedure for patients who want to effectively remove data (under certain specified circumstances and/or after a certain time). Patient education is required to ensure that there is a clear understanding that data removed still exists within the system and can be restored if authorised by the patient at a later date.

13. Penalties for misuse of information

The RACGP has grave concerns on penalties which may be applied. Based on the requirements of the privacy provisions as per the Australian Privacy Principles, there should be no additional penalties, civil or criminal that should be imposed. The emphasis should be on education and not penalties.