



RACGP

Royal Australian College of General Practitioners

Submission to the Senate Community Affairs References Committee inquiry into the My Health Record

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Introduction

The Royal Australian College of General Practitioners (RACGP) is Australia's largest professional general practice organisation representing over 38,000 members working in or towards a career in general practice. The RACGP sets and maintains the standards for quality clinical practice, education and training and research in Australian general practice.

The healthcare system in Australia, as in other developed countries, is facing many challenges including managing the burden of chronic diseases and caring for an aging population. The RACGP believe the ability to share patient information through the use of eHealth technologies has the potential to improve healthcare in Australia.

Executive summary:

The RACGP has a well established 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 eHealth technologies.

The RACGP welcomes the opportunity to provide written comment to the Senate Community Affairs References Committee inquiry into the My Health Record and our key recommendations include:

- strengthened privacy and security legislation to improve consumer and clinician confidence in the My Health Record system
- increased communications with consumer groups to improve digital health literacy to ensure consumers are informed about what My Health record is, the My Health Record expansion and how they can use the My Health Record to participate in their healthcare
- targeted consumer education on the My Health Record consumer controls, how the record is activated and the impacts of the current standing consent process regarding information uploaded and viewed by healthcare providers
- better articulation of the role of My Health Record as a consumer controlled record and the associated high value use cases
- improvements to the record activation process , whereby patients who have their record initially activated at a healthcare organisation are required to provide consent for such activation with evidence of this consent stored by the system operator
- strengthening the current privacy and accessibility provisions of minors healthcare information by authorised representatives.
- strengthening individual provider and other healthcare staff audit logging
- removing consumer addresses from documents uploaded to My Health Record
- continuing to support a national rollout of direct secure electronic communications between healthcare providers

Responses to terms of reference:

A. Expected benefits of the My Health Record system

The RACGP supports the vision for a nationally available electronic consumer health record. The current national system is My Health Record. With continued uptake by the healthcare sector, the RACGP believes My Health Record has the potential to improve healthcare in Australia. The RACGP supports the view consumers have a right to access their own healthcare data and share it with their healthcare providers.

The RACGP recognises there may be potential benefits for consumers including:

- increased consumer engagement with their health and health information
- tracking and managing their own health, particularly for those with chronic diseases
- decreasing the burden on them in communicating their medical history with providers.

For specific consumer populations such as travelling or itinerant patients without a usual GP or general practice, and patients receiving after hours or emergency care, My Health Record may provide healthcare providers with information they otherwise did not have access to, such as hospital discharge summaries, test results and medicines information. Access to this information has the potential to improve consumer healthcare outcomes.

Whilst these are yet to be realised, there may be expected benefits for healthcare providers, including the potential to:

- provide access to information when consulting with an out of context patient i.e. a healthcare provider can view information of a patient who does not frequent their practice on a regular basis
- provide access to information which they would not otherwise have access to i.e. hospital discharge summaries not sent directly to them, test results they have not ordered themselves
- provide access to information generated from a new or non-regular provider, where normal communication channels have failed
- reduce time chasing up information via telephone and other sources once My Health Record is integrated into a practice's workflow
- provide access to supplementary health information in an emergency
- assist in medicines management.

The My Health Record system may provide benefits to the overall healthcare system through:

- improvements in healthcare service delivery
- the secondary use of aggregated data to assist in the planning of an effective and efficient health system.

B. Decision to shift from opt-in to opt-out

The RACGP has not taken a formal position on whether My Health Record follows an opt-in or opt-out model but acknowledges the opt-in process has been expensive to implement. The RACGP understands in order for the system to work effectively in terms of achieving improved health outcomes, there is a critical mass that must be reached and for public confidence to be built into the system. In this instance, an opt-out system provides that critical mass.

My Health Record is a complex system. We believe an opt-out model that provides standing consent for healthcare providers to access and upload to a patient's record requires a broad and in-depth consumer awareness campaign. Consumers should be well informed about what a My Health Record contains, who can access the record, how it is accessed, and what access controls are available to them.

The RACGP believes there are a large number of consumers who remain unaware they must make a decision whether to have a My Health Record created for them and if they do not want one they need to take action to opt-out of having a record created.

Furthermore, it is not well known by consumers what the implications are in terms of how their shell record will be activated (known as a “trigger event”). A shell record is activated when either the consumer opens their record, or a healthcare provider searches for or uploads to a consumer’s record.

Once the record is activated the default access control settings effectively allow any healthcare provider with access to My Health Record to view, upload and download from a consumer’s My Health Record for the purposes of providing healthcare.

The RACGP recommends that:

- increased consumer awareness is provided in relation to the trigger event
- the process for activating a shell record is strengthened so that when the trigger event occurs, a positive consent statement from the consumer is electronically captured authorising activation of the shell record. This initial consent then activates the standing consent model of My Health Record
- consumers are prompted to review their access controls upon activation of their record
- consumer education should be funded and overseen by the Australian Digital Health Agency (ADHA)

Whilst patients will have questions for general practice teams regarding My Health Record, the RACGP believes general practice is not the appropriate primary communication channel for consumers to be informed about the system and whether to have a record created. General practice workflows would be significantly impacted if GPs were to take on this responsibility.

The RACGP is delivering an education and awareness campaign for general practice to ensure they understand the impacts on their teams and patients with the change to an opt-out model.

C. privacy and security, including concerns regarding:

i. Vulnerability of the system to unauthorised access

The RACGP recognises there are vulnerabilities in any system and that all parties within the system contribute to its security. My Health Record security is controlled by a number of safeguards, including policies and procedures implemented by participating healthcare provider organisations, the My Health Record system operator and through legislative governance.

The RACGP believes the design principles, legislation and penalties of the My Health Record system adequately meet the privacy and security measures required. The fact the system restricts access to healthcare provider organisations who are providing healthcare to an individual should control the risk of unauthorised access to records, i.e. to insurers and commercial enterprise.

The RACGP supports the current consumer controls, which provide consumers the opportunity to limit which healthcare organisations can access their record and to limit access to specific documents. The RACGP supports the requirement to store and retain My Health Record data in Australia, and is comfortable with the ongoing security framework comprising encryption and digital authentication processes, regular penetration testing and unusual activity monitoring.

The RACGP believes healthcare provider organisations share responsibility in preventing individual unauthorised access to My Health Record through local management initiatives including; practice team education, designation of regulatory roles within a practice, compliant management of Healthcare

Identifiers, strong password management within clinical information systems (CIS), and adherence to hardware and software requirements. The RACGP supports members through the development of guidance material including [Information Security in General Practice](#) which details and recommends essential business practice, policies and procedures to help protect general practice information systems.

Documents in My Health Record can contain consumer demographic details including their address and other sensitive information which is visible to any healthcare provider who accesses My Health Record. This information is not required in a consumer controlled record and creates unnecessary vulnerabilities by making patient data easily available.

The RACGP recommends that:

- healthcare organisation CIS must include the ability to log individual healthcare provider access and other team member access to a consumer's My Health Record from within their organisation
- the system operator should be able to track access by any healthcare provider to any consumer's My Health Record, irrespective of access through a CIS or via the provider portal, and irrespective of the provider authentication method (PRODA, NASH)
- the current legislative requirements be reviewed to reduce the significant administrative burden placed on general practice to meet these requirements which can leave practices vulnerable to risks that may outweigh the benefits of My Health Record and discourage adoption
- consumer addresses are removed from documents uploaded to the My Health Record

ii. Arrangements for third party access by law enforcement, government agencies, researchers and commercial interests,

The RACGP believes no identifiable information from a consumer's My Health Record be released without a court order. The RACGP has advocated for amendments to Section 70 of the *My Health Record Act* and is pleased Minister for Health, Mr Greg Hunt, has introduced legislation into the Parliament to strengthen these provisions. Strengthening privacy provisions will increase consumer confidence in the system.

The RACGP supports consumer's rights to make informed decisions regarding secondary use of the data within their My Health Record.

The RACGP supports the 'Framework to guide the secondary use of My Health Record system data' that prevents the release of secondary data for non-health-related purposes.

The RACGP recommends that:

- the ADHA consumer awareness campaign include information on what purposes consumers' secondary data may be used for and that consumers can opt-out of having their My Health Record data used for secondary purposes
- in regards to secondary use of My Health Record data, primary care researchers, including those in representative bodies such as the RACGP and outside of large research institutions, should be able to access and utilise de-identified and aggregated data (as determined by individual consumers under the current secondary data opt-out settings available). This would allow the building of an evidence base that supports the use and continued growth of the system, with the focus being on efficiency and improving healthcare outcomes, not clinician surveillance.

iii. Arrangements to exclude third party access arrangements to include any other party, including health or life insurers

The RACGP supports the 'Framework to guide the secondary use of My Health Record system data' and that provision of My Health Record data to insurance agencies is explicitly not permitted.

The RACGP recommends that:

- the 'Framework to guide the secondary use of My Health Record system data' is backed up by legislation to specifically prohibit requests from insurers to healthcare providers to provide information from a consumer's My Health Record
- general practice, via their representative body the RACGP, is involved in the review of the framework, planned to be conducted no more than two years from when the first dataset is released.

D. The Government's administration of the My Health Record system roll-out, including:

i. Public information campaign

Given the complexity of My Health Record, the RACGP believes ongoing, frequent, easily accessible information for the Australian population is required.

The ADHA consumer campaign has not broadly reached and educated the Australian population regarding My Health Record, preventing them from making a fully informed decision on having a My Health Record created for them.

Consumers need to understand the My Health Record is an online repository for documents and data, which contains information about their health and healthcare from various sources including the consumer themselves, their healthcare providers and Medicare.

The current campaign describes the My Health Record as "an online summary of your key health information" which is not completely accurate. It is not a 'summary', but can contain summary documents.

Additionally, the My Health Record, by design, cannot always provide a complete picture of a patient's health status and information contained in the record may not always be current.

The RACGP recommends that:

- the focus of communications should be on consumer controls, including security settings, access restrictions and default settings and the standing consent principle underlying healthcare provider access and upload
- the consumer awareness campaign better articulates what the My Health Record system is and is not.

ii. Prevalence of 'informed consent' amongst users

When a My Health Record is established, the healthcare consumer provides 'standing consent' for all healthcare organisations involved in their care to access that record and upload information. This standing consent applies until a patient explicitly communicates withdrawal of consent. There is no legal requirement for a healthcare provider to obtain consent from a patient on each occasion prior to uploading clinical information or to provide an opportunity for a patient to review clinical information prior to upload. However,

where a patient explicitly requests that specific information is not uploaded to My Health Record, the healthcare provider must comply with that directive.

As per the [RACGP position statement: My Health Record](#) the RACGP supports this consent model, on the proviso consumers are well informed as per [RACGP recommendations in item B](#) regarding the trigger event for a shell record being activated. Healthcare providers are under no obligation to make a decision about whether to upload information to My Health Record on behalf of patients, and should not unilaterally override a patient's standing consent. All decisions to upload content to My Health Record should be considered with reference to this principle. Where information is of a potentially sensitive nature, it may be prudent for healthcare providers to discuss the information with the patient prior to uploading it.

As evidenced by statistics of existing users, most consumers will not implement any restrictions on viewing or uploading information within their My Health Record.

The RACGP recommends that:

- a strengthened consumer awareness campaign is required to ensure all Australians are fully informed about My Health Record and access provisions under a standing consent model

E. Measures that are necessary to address community privacy concerns in the My Health Records system;

The RACGP has a number of recommendations to address community and general practice concerns. These include:

Increased communications to the Australian population

Whilst most patients reasonably expect their GP to access health data in a My Health Record, many consumers may have minimal understanding that other healthcare providers, such as pharmacists and allied health professionals, may have authority to access their My Health Record.

The RACGP recommends that:

- consumers are well informed regarding which healthcare providers are able to access their record
- consumers are well informed of the access controls available to them.

Minors

There is concern amongst GPs providing care for minors, as highlighted by attendees at numerous recent RACGP education sessions, that privacy of mature minors may be compromised through uploading of data to their My Health Record. In the majority of cases, a minor will not be aware they:

- have a My Health Record or will have one created if they, or their authorised representative do not opt-out
- may take control of their My Health Record at age 14 and;
- that their authorised representative has default access of their record until 18 years if they do not take control.

Whilst MBS and PBS data is not visible in a minor's My Health Record from age 14, the uploading of pathology reports, medicines information and other summary documents, may disclose health information the minor may wish to not share with their authorised representative.

The mechanism by which a minor takes control of their My Health Record is problematic in that it requires the creation of a MyGov account and a verification of identity procedure. It is questionable as to how many minors will have access to all the necessary documentation to take control of their own My Health Record, which includes Medicare details, evidence of address, bank account details and information regarding the last consultation for which a Medicare claim was made.

The RACGP recommends that:

- education of My Health Record be co-designed with youth and communicated via appropriate channels including social media and in-school education programs
- when a minor turns 13 years and 9 months the system operator writes to that minor advising them of their options in relation to the control of their My Health Record from age 14
- automatic access to a minor's My Health Record by the authorised representative ceases when the minor turns 14, without the need for the minor to take control of their record.
- that from age 14, until such time as the minor takes control of their My Health Record, or when they turn 18, all automatic data feeds are deactivated
- the process for minors taking control of their My Health Record is reviewed and simplified where possible.

The RACGP supports the current requirement for those under 14 to prove competency in order to take control of their My Health Record.

Improved consumer controls

The RACGP recommends that:

- increased and more specific consumer controls are introduced to allow consumers to set standing restrictions on the upload of certain classes of documents (i.e. medicine information or pathology reports) into their My Health Record rather than having to withdraw consent for each document which relies on consumer memory and is not done consistently. For example in the current environment if a consumer wants to withdraw consent for a medicine to be uploaded they need to direct the prescriber and dispenser not to upload this information at the time of prescribing and dispensing. However, to withdraw consent for any upload of pathology results to My Health Record, consumers need to utilise a 'Do not send to My Health Record' tick box on a printed form. Withdrawal of consent for documents to be uploaded should be controlled by the consumer consistently across the healthcare sector and via the My Health Record settings functionality.

Regular auditing

No system is infallible and information in databases can still be used inappropriately, regardless of the security levels and restrictions in place.

The RACGP recommends that:

- regular and random auditing, by the system operator, of consumer records accessed by healthcare providers is conducted and publicly reported.
- the current security and surveillance tools in use are communicated by the system operator which may instil greater confidence in the system amongst consumers and participating healthcare providers.

F. How My Health Record compares to alternative systems of digitising health records internationally;

The RACGP recognises there is a need for consumers to have access to their health information and at times, there is confusion as to whether My Health Record is a consumer or clinician controlled record. The model implemented in Australia is a consumer controlled record and therefore is not a clinical record. My Health Record is not a replacement for patient records kept at the local level and GPs, their practice nurses and other staff create and manage patient information in their practice's CIS. Using My Health Record is not mandatory for healthcare providers and remains an opt-in system for healthcare providers.

Internationally a number of systems have been implemented to address consumer access to health records, including health data exchanges. Consumer access directly to source systems such as hospital or general practice databases has been attempted in some locations.

The Open Notes movement is an example of a process that provides a resource to assist clinicians and healthcare systems share clinical notes with consumers. There are international learnings that can be taken from programs such as Open Notes where consumers are empowered to participate in their healthcare through direct access to clinician notes.

An in-depth comparison of international systems with My Health Record is difficult due to limited implementations and given such systems have been implemented with differing intentions. These vary from clinician only access to consumer only access. There appear to be limited attempts at implementation of a system that is aimed at both consumers and clinicians, particularly on such a large national scale and involving all healthcare providers.

G. any other matters.

Use of My Health Record as a potential additional source of information:

My Health Record is not designed to be used as a means of direct communication between healthcare providers. Information uploaded to My Health Record may or may not be accessed by healthcare providers. My Health Record is not a communications system. It remains essential for healthcare providers involved in the shared care of a consumer to continue to communicate directly with each other, ideally via secure electronic communications.

The RACGP regards interoperable secure electronic communications as an integral part of the broader eHealth system. Timely secure communications support continuity of care and clinical handover.

The RACGP recommends that:

- Australian Governments to continue to invest in the development and implementation of a national interoperable secure messaging framework
- all healthcare providers are educated about the appropriate use, roles and positioning of both secure electronic communications and My Health Record.

Recognising the role of general practice:

General practice is the location in which most Australians obtain primary healthcare. Two million Australians visit a GP weekly and 85% of the Australian population consult a GP on an annual basis. Consequently, general practice teams generate a large amount of data within My Health Record, including authorship of Shared Health Summaries (SHS).

A SHS is a key clinical document of the My Health Record system. It provides an overview of specific health information for a patient at a particular point in time, and contains current medicines, medical history, allergies, adverse reactions, and immunisations. This information might be particularly helpful to healthcare providers outside of the patient's usual general practice who are seeing the patient for urgent or unscheduled care. A consumer's Nominated Healthcare Provider creates a SHS. The Nominated Healthcare Provider is the regular care provider, and for most Australians this is their usual GP.

In addition to creating clinical content for documents such as SHS, participating in My Health Record also involves ensuring the necessary practice policies and processes are established and maintained to meet technology and regulatory requirements. This time and effort invested may appear to have little initial direct benefit to the general practice, as the relevant information is already in the local clinical information system. There is, however, a potential benefit to other healthcare providers and therefore the consumer. As a key contributor to My Health Record, through the creation of SHS and other forms of health data, general practice should be financially supported to participate through an appropriate incentive scheme.

The RACGP does not support the current Practice Incentive Payment – eHealth Initiative (ePIP) distribution, under which benefits are paid solely to the practice, and which uses arbitrary upload targets as a criterion for eligibility.

The RACGP recommends that:

- an additional incentive is introduced that is service-based which is paid to the individual healthcare provider responsible for upload, and supports the upload of accurate, high-quality data.

Privacy and security for victims of family violence and their children:

The RACGP recognises victims of domestic violence and their children are a vulnerable population and believe more needs to be done to ensure the safety and privacy of such individuals is protected. There is currently an onus on the consumer to be well informed of the existence of a My Health Record and the access controls available to them.

Privacy of healthcare organisation employees:

Privacy concerns have been raised by RACGP members regarding employees of healthcare organisations connected to the My Health Record. An employee's My Health Record may be accessible to the employer (healthcare organisation), if that healthcare organisation provides healthcare to that employee.

Usability

Information added to My Health Record by clinicians is added via CIS functionality which varies between systems. This presents challenges for clinicians in engaging with My Health Record and is a significant barrier to adoption. General practices not using the latest versions of CIS software may not have all of the My Health Record functions.

The CIS functionality of the My Health Record requires multiple interactions with the software that are not consistent with the other functionality across the CIS. Clinical usability is a critical issue and while the RACGP recognises work has been done to improve this, the RACGP believes more can be done and that minimum usability requirements are needed.

The RACGP recommends that:

- increased focus is placed on the design and integration of My Health Record with local clinical software
- systems and functionality are designed in conjunction with clinicians and software developers to ensure systems are fit for purpose and align with existing clinical workflow.

Requested improvements to the My Health Record system by GPs include:

- that a consumer's My Health Record clearly identifies the Nominated Healthcare Provider or usual GP by displaying the name of the GP and the associated practice detail on the consumer's My Health Record home (landing) page. This would better support continuity of care by allowing other healthcare providers to more readily identify the consumer's usual GP or general practice
- an additional field for language spoken by the consumer in the My Health Record, including whether an interpreter is required
- improvements to the accessibility of records from the Australian Immunisation Register (AIR) for adults. Information from the AIR is currently accessible in consumers My Health Record via the Childhood Development tab (even in adult records) and is only visible to some healthcare providers through their CIS
- that there be a clear and direct channel for clinician and software developer system issues to be addressed, corrected and the system improved upon.