The Royal Australian and New Zealand College of Radiologists®

RANZCR Response to the Senate Community Affairs References Committee Inquiry into My Health Record system

Thank you for the opportunity to contribute to this important consultation.

About The Royal Australian and New Zealand College of Radiologists

The Royal Australian and New Zealand College of Radiologists (RANZCR) is the peak body advancing patient care and quality standards in the clinical radiology and radiation oncology sectors. It represents over 4,000 medical specialist members in Australia and New Zealand.

Clinical radiology relates to the diagnosis or treatment of a patient through the use of medical imaging. This includes the use of plain X-ray, computed tomography (CT), magnetic resonance imaging (MRI), ultrasound, nuclear medicine and PET to produce images that are interpreted by a radiologist to aid them and other clinicians in the diagnosis and treatment of their patients. This includes pre-natal care (obstetric ultrasounds), to babies and children through to the elderly, from dating scans to non-invasive treatment for cancer. Radiology supports clinical decision-making throughout people's lives.

The speciality of radiation oncology focuses on the use of radiation to treat cancer and other diseases. Radiation therapy is an effective, safe and cost-effective method of treating cancer and is involved in 40% of cancer cures. Unfortunately, while one in two cancer patients would benefit from radiation therapy, only about one in three will actually receive the treatment. One major reason for this is a lack of awareness about radiation therapy.

General comments on RANZCR and My Health Record

RANZCR has been active in the digital health space for many years, due to the inherently digital nature of current imaging technologies. Clinical radiology and radiation oncology went digital before other parts of medicine. We have worked closely with the Australian Digital Health Agency (Agency), as we did with its predecessor (NeHTA), in the development of policies, standards, and a digital health environment in Australia.

Digital health and the My Health Record (MyHR) provide numerous opportunities for delivering better quality and more informed care, as well as improving access to healthcare, particularly for those in regional and remote areas. However, access to sensitive health data needs to be managed carefully, with due regard for privacy considerations, workability, and the information needs of health practitioners utilising the system.

We have had particular involvement in policy work and consultations on MyHR since its initial inception some years back as the Personally Controlled Electronic Health Record (PCEHR). RANZCR's Faculty of Clinical Radiology is currently working with the Agency on the uploading of radiologist reports from public and private practices into MyHR. We are jointly pursuing such uploads in order to improve access to clinical radiologist reports and reduce unnecessary duplication of imaging studies. However, attention to the details of the uploading procedure in radiology is very important, to prevent adverse impacts on the delivery of patient care.

As technology continues to evolve, so too will the potential of MyHR, in ways we cannot yet fully anticipate.

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a. the expected benefits of the My Health Record system;

The My Health Record system has the potential to offer a wide range of benefits to Australians including improving the quality of care, reducing unnecessary tests, and allowing patients and their doctors greater access to the patient's health information. Reducing the fragmentation of health information and increasing information sharing will doubtless benefit patients and health practitioners alike. This is especially true in the event of a new patient presentation, where the system can give a doctor access to historic information about that individual's care.

However, the system will only work if due regard is paid to privacy considerations, workflow, and the needs of health practitioners utilising the system.

Barriers to Uptake in Radiology

A significant restriction in the realisation of these benefits is the lack of uptake by radiology providers. At present, only small numbers of radiology providers are uploading clinical radiologist reports to My Health Record. There are several reasons for this.

Choice of Priorities:

RANZCR has been active in the consideration of digital health standards and projects for many years. We and other radiology stakeholders (particularly ADIA, which represents private practices) were not given input to the Agency's priorities in this field when they were set, which meant that we have struggled since then to agree to a shared set of priorities. RANZCR is working with the Agency and other radiology stakeholders to agree on common priorities, and a work plan to address those.

Recognition of Costs:

Appropriate recognition of implementation costs for radiology practices, and support for the changes they need to make to adopt My Health Record, will be critical to the success of My Health Record in radiology. This support should cover the costs of training practice staff, upgrades of practice management systems (beyond the specific RIS software upgrade for report uploads, which the Agency has funded) and other ongoing administrative costs associated with requirements around digital health, for example compliance with new privacy and consent obligations. Consideration should also be given to follow-on cost implications for radiology practices e.g. those resulting from requests for previous reports (and images). RANZCR and ADIA commissioned research into implementation costs for radiology practices, which found that these costs amounted to $4 per scan. This research is included at Appendix 1. Radiology providers treat very large numbers of patients every year. For this reason, administrative costs associated with digital health, while relatively minor per patient, can become burdensome and costly in aggregate.

Further, we are concerned by the potential obligation for a radiologist or radiology practice to review every patient's My Health Record before completing their clinical assessment. To access the My Health Record for every patient would be excessively onerous and unrealistic. We are concerned that by not reviewing the patient's record, a doctor would expose themselves up to medico-legal risk.

Practices cannot absorb these additional costs when radiology services have not been indexed for almost 20 years.

RANZCR would welcome a recommendation from the Senate Inquiry that the Government consider funding for radiology providers that recognizes the additional work and expense required to upload to MHR.

Potential administrative burden of identity matching in difficult cases:

Consideration should also be given to the proportion of patients who will have problems with their IHI/Medicare online verification. Anecdotal feedback from the sector suggests that a small section (5%) of the community have administrative issues with their Medicare details (incorrect details, no Medicare number etc). It is likely that this issue will persist with adoption of the IHI and continue to complicate attempts at patient verification and sharing of information to correct records. These issues should be considered in the design of supportive measures.

Conflation of Pathology and Radiology Workflows:

There has, unfortunately, been a persistent view from the Agency that pathology and diagnostic imaging / radiology are equivalent, with insufficient consideration given to a tailored approach to each specialty. This is despite a number of representations from RANZCR that the service models, patient flows, and market structures are very different. This has led to inappropriate processes or proposals for the implementation of MyHR within radiology.

RANZCR would welcome a recommendation from the Senate Inquiry that the Agency engage more comprehensively with the radiology sector.

Description of the Sector:

RANZCR also believes that consumers do not generally understand the term 'diagnostic imaging'. We have requested that the Agency use the term 'radiology', which is better understood by patients as consumers.

b. the decision to shift from opt-in to opt-out;

RANZCR supported the move to an opt-out system, on the basis that wider use by consumers would lead to increased support from healthcare providers. RANZCR has previously noted that the lack of uptake of MyHR was discouraging utilisation by healthcare professionals.

However, consumers must be confident that the MyHR system will improve their health outcomes, and that the system has appropriate protections in place for the security and privacy of sensitive health information.

Unfortunately, insufficient effort was made to explain to the public what the MyHR is, how it can be secured, and its benefits for patients, before the launch of the recent opt-out period.

c. privacy and security, including concerns regarding:

There are two important privacy considerations regarding the upload of radiology reports to MyHR. The first is how providers manage instructions to not upload particular reports. Second is the status of persons with HIV and the interaction with the *Public Health Act 2010 (NSW).*

Managing instructions to not upload

The current system for consent in relation to radiology is that a person who has a My Health Record provides standing consent for the upload of information to their record. Where a person does not want a particular report to be uploaded, they must make a specific request that it not be uploaded, either to their referring practitioner, or to the radiology practice.

Patients who do request that reports not be uploaded therefore present a new challenge to radiology practice systems. Appropriate procedures and training for staff must be in place to ensure that a patient's wishes are captured and respected. This places a burden on radiology providers to invest in these adjustments, as well as introducing legal risk if there is an unintended error by either the IT system or a staff member. This is one of the reasons that the widespread uptake of the MyHR will increase costs for radiology practices, and hence RANZCR has repeatedly advocated to the Agency that radiology practices receive financial support to transition to the My Health Record system.

Public Health Act (NSW)

Legislation exists in NSW managing the privacy of persons with HIV. The Public Health Act requires healthcare practitioners to take reasonable steps to prevent information about that person's condition or treatment from being disclosed, except to another healthcare practitioner involved in that patient's care. This creates an issue in radiology, because the model of standing consent for the upload of reports to MyHR is confused by the requirement of the Public Health Act to seek express consent from the patient for the sharing of this type of sensitive data.

RANZCR has sought legal advice as to the obligations on radiology providers in these circumstances. This advice states that radiologists would still be able to upload a report to MyHR that refers to a patient's HIV status (known, or perhaps implied by radiological findings), based on the assumption that health practitioners accessing a person's MyHR are doing so as part of care or treatment to the patient. RANZCR is still awaiting clarity from the NSW Government on how this will be managed in public hospitals.

i. the vulnerability of the system to unauthorised access,

Unauthorised access is a risk in the operation of the My Health Record system, particularly for sensitive results which might appear in a radiologist's report.

RANZCR understands that access to MyHR is granted to all AHPRA registered healthcare professionals. This is important to allow members of the radiology team, such as radiographers, to source previous reports and images which allow the team to better ascertain the nature of the current clinical problem and assess whether a clinical condition has progressed between appointments at different practices.

There is always a balance to strike in access to health information. The MyHR system needs to be robust and allow traceability of any offender in the event of unauthorised access or security breach. It is already possible to sanction an individual for misuse of healthcare information. However, it is understood that current arrangements may only allow identification of the organisation from which a MyHR was accessed, not the specific individual within that organisation. RANZCR would expect any healthcare professional to be

able to justify why they viewed a particular health record, for example by demonstrating that the patient in question attended their practice or hospital for healthcare services.

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

RANZCR would be very concerned if individuals who are not involved in the delivery of care have access to patient records, except in certain special circumstances. We were pleased by the recent announcement by the Health Minister of tighter restrictions on access for law enforcement purposes.

We support the My Health Records Amendment (Strengthening Privacy) Bill 2018 which will require a court order to authorise disclosure of a person's record to law enforcement agencies and other government bodies.

The My Health Record has the potential to provide a wealth of information and data. Analysis ('secondary use') of this could have tremendous benefits for public health or service planning, however the specifics about how this information is shared are critical, since health information can contain very sensitive and personal data.

Once a patient's data is shared, it cannot be unshared.

RANZCR believes that a cautious approach should be taken, which would involve a range of up-front and ongoing safeguards to ensure judicious and appropriate secondary use of My Health Record data, including radiologist reports. This position is outlined more completely in our response to the Australian Government, Department of Health, *Framework for the Secondary Use of My Health Record Systems Data Consultation*[1].

RANZCR suggests the following safeguards as a minimum:

- Sharing of data within Australia only
- No revenues for government agencies from sharing of this information, since that would create perverse incentives for dissemination of sensitive information
- A clear and unambiguous definition of usage for public health purposes, which is demonstrably in the public interest, to be considered and applied by an ethics committee
- Binding contractual penalties including criminal penalties for misuse
- Approved users of secondary data bound by undertakings on confidentiality
- Information not being made available to parties with commercial interests
- Debar subsequent sharing of information with other agents or companies.

Further, RANZCR believes that the use of the terms 'not-for-profit' and 'non-profit' should be avoided, as they potentially refer to a wide range of entities involved in the delivery of health services such as hospitals or membership associations representing service providers, who would not have the same motives as universities seeking to do academic research. Commercial entities should not have access to MyHR data, including not-for-profits involved in the delivery of healthcare services, or the sale of related products such as insurance.

[1] https://www.ranzcr.com/college/document-library/ranzcr-submission-to-the-framework-for-the-secondary-use-of-my-health-record-systems-data-consultation

There is a complex web of potential uses of this information, many of which are evolving, for example the application of artificial intelligence and deep learning. It is also increasingly possible to re-identify individuals from de-identified data, particularly when the latter are correlated with other data sources.

At this stage, it is not possible to conceive of all of these potential uses or their ramifications, and it would be prudent to err very much on the side of caution.

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

As outlined in the response above, RANZCR believes that a cautious approach should be taken which would involve a range of up-front and ongoing safeguards to ensure judicious and appropriate secondary use of My Health Record data, including radiologist reports.

The proposed restrictions listed above include suggestions that commercial providers or those 'not-for-profit' entities that are involved in the delivery of health services not be granted access to data.

Above all, it is our view that a conservative approach be taken when considering whether to provide access to a person's health information.

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

i. the public information campaign,

RANZCR has had some concerns with the public information campaign relating to the MyHR. For example, we have been concerned that there has not been more emphasis on the fact that only a small component of a person's health information will be uploaded, and on the restrictions around the use of this information. Although arrangements are being put in place for radiology reports to be uploaded to MyHR, it is likely that in the early part of the "opt-out" era, very few reports will be available in the MyHR, and that not all newly generated reports will find their way to the MyHR. This may particularly be an issue with reports made in response to specialist referrals. Members of the public will likely not be aware that even if a radiology report is present in the MyHR, the associated images will not be available there (even though this point is made in the Agency factsheets).

As noted above, there was insufficient effort to explain to the public what a MyHR is, and what its safeguards and benefits are, before the launch into the opt-out period.

ii. the prevalence of 'informed consent' amongst users;

RANZCR believes that informed consent requires a proper understanding of the decision being made and the consequences of that decision for the individual. The Agency has provided a range of information materials around this which we expect the Senate Committee will consider in detail.

e. measures that are necessary to address community privacy concerns in the My Health Record system;

As mentioned above, traceability of access to a specific individual is a key consideration here.

f. how My Health Record compares to alternative systems of digitising health records internationally;

The MyHR seeks to accumulate pdf copies of documents concerning a patient's health but makes no guarantee of contemporaneity or completeness to potential users.

Data in pdf format is not readily searchable, and very little attempt has been made to standardize the terminology used within these documents. For radiology, the hundreds of examination types available are to be grouped roughly by imaging modality (X-ray, ultrasound, CT, etc) and one of 14 anatomic regions.

Internationally, there has recently been a strong move towards (appropriately authorized) direct access to the "source of truth'' for health data, the electronic record generated by the provider at the time of the encounter. Furthermore, this data will be provided in a structured form (using the FHIR health computing language). There has also been much work at a lower level to develop standardized terminologies (particularly, in radiology, a standardized list of orderable examinations), so that a particular examination is given the same name by all systems, and all systems 'understand' exactly what is meant by that orderable ('semantic interoperability'). This last feature is critical to the development of useful applications for decision support, assisted diagnosis etc.

Much of the software used in Australian radiology practices, and in hospital EHRs, has been, and will continue to be, developed by large international firms. Many of these companies are participating in the American "Argonaut" initiative, which seeks to promote the use of open records, FHIR, and semantic interoperability, in order to accelerate the development of applications that will significantly improve timely access to relevant health data, and thus improve healthcare. This approach also avoids the difficulties and dangers of a single massive central database.

g. any other matters.

<u>Access to historic images</u>

RANZCR has called for better access to previous ('historic') radiology images for a number of years, in order to enhance the information available to a radiologist or other doctor when a patient attends for health care. This is clinically beneficial and would also reduce duplicate imaging, for example when another doctor is forced to request further imaging because they cannot access recent radiology results from a test done elsewhere. For this reason, RANZCR and the Australian Diagnostic Imaging Association developed a policy paper in 2013 titled *Securing Quality Outcomes: Systemised Access to Digital Images*. This paper is available via the RANZCR website[2].

RANZCR has proposed that better access to historic radiology images should feature as the next enhancement of MyHR, possibly including a digital link to the site where the particular set of radiology images in question is stored. Further, historic images are required by other clinicians when providing future care and better availability of these would have a big impact

[2] https://www.ranzcr.com/college/document-library/securing-quality-outcomes-systemised-access-to-digital-images-2013

on reducing repeat imaging that is currently conducted because a healthcare practitioner does not have access to previous results. The “Securing Quality Outcomes” document was written at a time when a central registry of exams (NOT a central repository of exams) was the most practical approach to guiding remote image access; since then, with the development of DICOMweb technologies, the need for a central registry of images has become less certain, and the document would need to be reviewed in this light before any attempt at implementation.

Individual health identifier

Adoption of an appropriate universal health identifier will be critical to the ongoing success of the My Health Record. Radiology practices are still required to look up and validate Medicare numbers to ensure they have the correct patient’s information and health record. However, given that there are many different types of Medicare number, this can often be challenging. The incorporation of the Individual Health Identifier in diagnostic imaging will take time and resources, however it would assist greatly in confirming the identity of the patient and improving access to health information held at other sites, once used across the system.

eReferral

RANZCR was very concerned by recent media reports that suggested Tasmania was developing and trialling a state wide eReferral system. Depending on its structure, an eReferral system in radiology has the potential to significantly reduce patient choice of imaging provider, particularly if a point-to-point solution is adopted. Patient choice of provider has been a key principle in the Medicare arrangements for radiology for many years. RANZCR has developed an eReferral position statement that outlines the patient protection provisions that should be included in any eReferral system.

Conclusion

Thank you for the opportunity to contribute to this discussion.

Advancements in digital health provides great opportunities for improving access to high quality care, no matter where one lives. However, it is essential that a digital health strategy properly considers how health practitioners will access information and how digital health improvements will interact with each part of our health system.

The Royal Australian and New Zealand College of Radiologists
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