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RACP Submission to Inquiry into the My Health Record system

September 2018

Introduction

The Royal Australasian College of Physicians (RACP) welcomes the opportunity to provide a submission to the Community Affairs References Committee inquiry into the My Health Record (MHR) system.

This submission addresses the following terms of reference of the inquiry in the following order:

- The section on the expected benefits of MHR addresses term of reference (a)
- The section on the expected risks of MHR addresses term of reference (c) dealing with privacy and security concerns but also encompasses other risks which we have uncovered in consultation with our members
- The section on third party access for research purposes expands further on a separate point within term of reference (c)
- The section on the merits of opt in versus opt out addresses term of reference (b).
- A set of recommendations arising from our comments is provided in the final section of this submission. This includes a set of recommendations on how the public education campaign for MHR could be improved.

Where relevant this submission also comments on the My Health Records Amendment (Strengthening Privacy) Bill 2018 which is the subject of a separate inquiry.

Expected benefits of MHR

An estimated 18 per cent of medical errors in Australia are due to incomplete or inaccurate patient information[1] while medical tests are currently duplicated for over 10 per cent of adults with chronic conditions.[2] Annually, approximately 230,000 Australians are hospitalised due to medication error and adverse drug reactions.[3] Reducing the fragmentation of patient health information and increasing opportunities for the collection and use of patient health and medical information through a technology such as the MHR which serves as an online summary, allowing patients to share and control their health information with doctors, hospitals and other healthcare providers can help reduce medical error due to incorrect data entry, illegible handwriting and inaccurate or incomplete information being entered. It can also ensure information is available to the clinician even where the patient is not in a capacity to inform the clinician of previous medical history (for instance where the patient is unconscious or otherwise cognitively impaired).

Moreover, by acting as a central repository which allows doctors to review whatever tests and treatments have already been provided to their patients by other clinicians, the MHR has the potential to significantly improve the quality of care provided to patients suffering from chronic disease and multiple co-morbidities given that such patients have higher than average levels of hospitalizations, outpatient visits, and subspecialist referrals[4], factors which are likely to result in duplication of tests performed. As testing is associated with some risks (however small) such as radiation exposure and infection, there are direct patient benefits reflected in increased healthcare safety and quality from the corresponding reduction in unnecessary testing.

In summary, as outlined in our recent statement welcoming the introduction of MHR, we expect that if the MHR can facilitate greater and more effective use of digital health that this would yield patient benefits due to:

- reduced frequencies of medication error and adverse drug events
- reduced errors due to illegible handwriting, faxes and lost paper records
- better management of patients with complex illnesses who need to see multiple health care providers by facilitating continuity of care
- better targeted treatment of renal and other chronic conditions in remote Indigenous communities; and
- reductions in duplication and overutilization of medical imaging and pathology requests.

From these primary patient health benefits, we would also expect system benefits such as reduced fragmentation in the provision of healthcare services resulting in increased efficiency in service provision, reduced costs including out of pocket costs associated with unnecessary tests, referrals and services and reduced healthcare waste leading to the freeing up of healthcare resources that were previously tied up in duplicated tests.

The 'review' function facilitated by the MHR of allowing clinicians to read and review opinions and decisions made by other clinicians on the same patient would be expected to encourage better quality of record keeping practices insofar as clinicians will be aware that their records are more widely available for review by their peers and other clinicians. While errors can also be perpetuated and entrenched in the MHR, arguably they are more open to correction and revision under this increased transparency of having a central record for clinician notes. Whatever the imperfections of the MHR, this is still an improvement to the current system where there can be a complete lack of visibility (for other clinicians from the main clinician) of what is contained in a practice record. For some clinicians practising in very specialised areas this enhanced transparency of clinician notes is especially important. For instance:

- where a clinician disagrees with the previous clinician's diagnosis, access to previous clinician notes can facilitate the resolution of ambiguities and disagreements
- review of clinical notes can reduce opportunities for 'doctor shopping' by patients who are addicted to prescription medicines
- 63% of genetic medicine specialists polled by the Human Genetics Society of Australasia (who responded) support the proposition that availability of information in the MHR would be beneficial in helping them to diagnose and manage patients with genetic conditions.[5]

More generally the review and information repository functions are one of the key characteristics of MHR that makes it an important building block for better integrated care. Even though interactive functionality of the MHR is currently limited, having this infrastructure in place can be an important first step for adding more sophisticated functionality to the platform later.

There are also benefits which flow from the secondary use of appropriately deidentified MHR data in health services and medical research. These include benefits from better use of personalised and genomic medicine arising from new findings from such research and better targeting and design of health services. This is discussed in further detail in the section on 'Third party access for research purposes'.

While the benefits from MHR can be significant, these are premised on wide uptake by both clinicians and patients. The issues which may be hindering patient confidence in MHR and therefore hindering patient uptake are discussed in the next section.

Among clinicians, incentives are only currently provided to GPs to sign up and participate in MHR. The quick and efficient sharing of patient information between GPs and specialists would constitute one of the benefits of the MHR. However, this benefit is unlikely to be achieved without better engagement and buy-in from specialist physicians. As we have argued in a previous submission to a review of what was then known as the Personally Controlled Electronic Health Record, [6] we believe that comparable incentives to what are currently provided to GPs should also be provided to hospital and community-based specialist physicians if the goal is to maximise broad clinician uptake and fully leverage the benefits of MHR.

A further stage in the evolution of the MHR would be to use it to provide customised advice both to patients and their physicians from medical colleges (for instance in the form of approved clinical guidelines and other recommendations), as has been suggested recently by the Productivity Commission.[7] For instance, patients with chronic conditions (e.g. diabetes) could get regular reminders of tests or medications that they need to take while clinicians could receive prompts on low-value or inappropriate tests as identified by clinician approved guidelines such as RACP Evolve recommendations and Choosing Wisely recommendations from other medical Colleges.

Potential risks of MHR

According to recent data from the Australian Digital Health Agency, more than 6 million Australians currently are covered by MHR.[8] Almost seven million clinical documents, 22 million prescription documents and more than 745 million Medicare records have been uploaded. However, uptake among clinicians is still low, as approximately 13,708 healthcare provider organisations have been connected as of 2 September 2018, out of around 900,000.[9]

Risks from incompleteness of patient records

Ultimately, the usefulness of the MHR will depend on the quality as well as the comprehensiveness of the data uploaded. There are two dimensions to comprehensiveness. There is firstly the extent of coverage of the MHR

(of both patients and clinicians). Secondly there is the question of the completeness of the patient record. However, there will realistically be limits on this comprehensiveness because some people may choose to opt-out. In addition, under current provisions, people are also able to limit which healthcare provider organisations can access their MHR or restrict access to selected part of their record. These choices must be respected as a matter of patient autonomy. However, the possible incompleteness of the patient record introduces some risks to patient safety if clinicians treat it as a complete record and use it as a substitute for having an appropriate conversation with the patient or pursuing further investigations as required.

An additional complication that was raised by consultation with infectious medicine physicians is that some pathology labs have decided not to upload results of some tests onto the MHR. Thus, there is not just the risk of incompleteness because of patients exercising access controls but also risks of incompleteness due to some test results not being uploaded as a matter of policy.

The Australian and New Zealand Society for Geriatric Medicine which is a RACP affiliated specialty society has also noted that advance care planning documents (statutory and informal documents) can only be uploaded by the patient, not the GP or other health provider. This may also result in an incomplete MHR.

Privacy protections to increase community confidence in MHR

Wider community engagement in MHR (including comprehensiveness of patient records available to clinicians) can be enhanced if the general community is sufficiently confident about the privacy protections already afforded them so they are both willing to opt in to the system and retain all of their data on the record. In this respect, the additional protection offered in the Health Records Amendment (Strengthening Privacy) Bill 2018 (the Strengthening Privacy Bill) which confirms the ability of law enforcement agencies and government agencies to access MHR data without a court order or the patient's consent should not be seen as a 'trade-off' but as a means of building up the community's confidence in MHR. As argued in the Explanatory Memorandum to the Strengthening Privacy Bill:[10]
Trust and confidence in the My Health Record system is paramount to engagement and participation in the My Health Record system. Without restricting when information can be accessed and used, people would not be willing to share their information through this system

A second major change introduced by the Bill is to require permanent deletion of health information stored in a person's MHR if that person decides to cancel their MHR. While commendable from a privacy perspective, it is worth noting that this provision may introduce some additional complications which need to be managed. One potential impact of this change is to increase the legal risk for practitioners who have previously relied on patient information contained in a MHR that is subsequently deleted. A second impact is that if a patient subsequently wishes to reinstate their MHR. it will have permanent gaps due to the record being deleted.

Managing sensitive data

Concerns have been raised by some members that the accessibility of test and other diagnostic data or clinician notes to patients via their MHR may lead to unnecessary anxiety or misunderstanding. For instance, this concern has been raised by genetic testing specialists and medical oncologists. In the case of genetic testing, genetic specialists are also concerned that even non-genetics health professionals can be prone to misinterpretation of genetic testing results and then end up causing unnecessary anxiety in their patients. However, in mitigation of this, we note that there is a period of time available before a test is "uploaded" and visible to a patient. Thus, ideally clinicians should use this window to discuss sensitive results with patients if they are not doing so already. However, given that this scenario of patients having better access to clinician notes is a relatively new scenario generated by the introduction of MHR, there is a case for conducting a renewed education campaign targeted at clinicians reminding them of the renewed need for patient dialogue and advising them of their responsibilities in properly counselling their patients about how to read and interpret tests results.

There are some additional privacy concerns unique to some patient groups which require further consideration:

- Marginalised and vulnerable populations such as those with sensitive diagnoses (such as HIV and mental health issues), people who use drugs, sex workers and victims of domestic violence are at risk

of having their employment and other opportunities compromised in the event of a privacy breach. While the Strengthening Privacy Bill addresses some of these concerns, it is recommended that there should be stronger wording on the privacy protections for sensitive diagnoses. This is more so as having a comprehensive health record in one place increases the risk of privacy breach.

- Adolescent patients may be discouraged from seeing a doctor for sensitive health issues if information about their consultations is accessible to their parents or guardians while confidentiality has been shown to improve young people's willingness to seek early medical intervention.[11] While under existing legislation, teenagers aged 14 and over are able to keep their medical records private from their parents or guardians, they must be proactive in changing their settings and making requests of their health providers. We therefore recommend that to better address this, the MHR 'default' should be automatically shifted to the control of the young person once they turn 14, with no obligation for parental access, as has been proposed by the Australian Association for Adolescent Health.
- Finally, there are remaining serious issues that should be addressed regarding access in cases of child abuse, family dysfunction and domestic violence where access may need to be protected. Currently this can only be done with a court order.

It would be preferable that all these issues are resolved before the opt-out period expires which may be an additional argument for extending it further (see the section on 'Opt in vs opt out').

Third party access for research purposes

Subject to some minor caveats, the RACP supports the Framework to guide the secondary use of My Health Record system data ('the Framework) as a good proposed approach for addressing issues relating to third party access for research purposes. Under this Framework, 'secondary' use is defined as use for research, policy and planning purposes. In November 2017 the RACP made a submission to the discussion paper on the Framework. Our submission emphasised that the policy objective of any third-party access to MHR data should be to drive high-quality research to improve health, including by promoting high-value evidence-based care. The RACP recognises that the use of MHR data for secondary purposes as defined under the Framework can inform population-based health interventions and preventive strategies and improve the evaluation thereof. For example:

- The role of MHR data in improving medicine safety and vaccine effectiveness is potentially considerable, and it is an invaluable way of improving pharmacovigilance and quality use of medicine, including for biologics and emerging categories such as genomic medicine. For instance, a recent Australian evaluation discovered there was a high degree of agreement between data extracted from general practice electronic health records (EHRs) and self-reported information from patients regarding contemporaneous influenza vaccinations.[12] This suggests that with a central repository of information like the MHR, the potential benefits to public health surveillance may be even greater.
- Linking hospitalisation rates with community-based care for the purposes of identifying and analysing regional variation (among other variables) using data from MHR or using MHR data to supplement existing data has the potential to encourage better health system planning and more equitable allocation of health resources. This has the potential to facilitate continuous quality improvement of clinical services and of health system performance more generally.

The College's position is that access for these secondary purposes should be researcher and project neutral (subject to appropriate safeguards). Our previous submission also emphasised the need for specific consideration of principles to guide the secondary use of data pertaining to Aboriginal and Torres Strait Islander peoples and pointed out that a functional and effective Framework is not a substitute for appropriate ethics approval of particular projects.

The final Framework, which was released in May 2018, has many features which are broadly consistent with our recommendations in that submission including the following:[13]

- Consumers can opt out of having their MHR data being used for secondary purposes
- MHR system data cannot be used for **exclusively** commercial and non-health related purposes nor will its provision to insurance agencies be permitted. However commercial organisations may propose uses that could be approved if they can be demonstrated to be consistent with 'research and public health purposes' and is likely to generate public health benefits and/or be in the public interest.
- Applications to be primarily based on the use of data, not the user.
- The Data Governance Board which implements the Framework will give specific consideration to use of data pertaining to Aboriginal and Torres Strait Islander people and communities.

- Ethics approval must apply to applications involving identified data and may apply to applications involving de-identified data (on a case by case basis).
- The Board to establish and maintain a public register of requests for access to MHR system data for secondary use.

The RACP is also highly supportive of the Framework's provision that the Data Governance Board may permit the linkage of MHR system data with other data sources if the use of the data is assessed to be of public benefit. Given the current high degree of fragmentation of health data sources, using the MHR as the basis for further data linkage with other sources can generate significant benefits for research, policy and planning purposes.

However, there were additional recommendations in the College submission which should be considered and followed up by the Committee to ensure smoother rollout of this Framework and ensure that community concerns on privacy are appropriately addressed:

- The Data Governance Board should develop appropriate principles and data governance arrangements for data pertaining to Aboriginal and Torres Strait Islander people and communities in collaboration with national Aboriginal community representative bodies such as the National Aboriginal Community Controlled Health Organisation (NACCHO) and State and Territory-based Affiliates of NACCHO, and Torres Strait Islander specific authorities. Where possible, secondary use of data pertaining to Aboriginal peoples and Torres Strait Islanders should require approval from Aboriginal HRECs (Human Research Ethics Committees).
- To build support for third party access to MHR data for these primarily research-based purposes, there needs to be ongoing communication on the benefits to patients and to Australian society that extends beyond simple assurances that privacy will be preserved.
- In parallel with this, steps should be taken to educate healthcare providers (of all professions) about the distinction between using MHR for its primary purpose—providing health care to an individual patient—and all other purposes, which are secondary. This is particularly important given easy health practitioner access to MHR and the temptation to access it for other purposes that may not meet the criteria of the Framework.

Opt-in versus opt-out

In a previous submission the RACP expressed in-principle support for an opt-out model as a means of ensuring critical mass participation.[14] We retain our in-principle support for opt-out while recognising that the implementation of the opt-out model and the associated public education campaign has not been be a smooth process, as we continue to receive feedback from some members that their patients are still not fully aware of their rights under MHR. For instance, the Human Genetics Society of Australasia conducted a survey of its members and 80 per cent who responded said that they did not think that the public have been provided with adequate information to make an informed decision on whether to opt out of MHR. This was also a significant viewpoint among the members who responded to our call for feedback in developing this submission.

At the same time, we recognise that the MHR had previously been covered by an opt-in process and the decision was made to move to opt-out because adoption was regarded as too slow under opt-in, a development which was anticipated in our previous submission.[15] In addition, moving from opt-out back to opt-in means changing the approach a second time, thus compounding whatever confusion may have originally been caused by shifting from opt in to opt-out. On these grounds, we recommend that it would be more appropriate to retain the opt-out approach to reduce the risk of further confusion within the general community about the status of their MHR coverage, and instead focus on providing a more extensive community education campaign about opt out to ensure that resulting community choices on MHR coverage reflect informed consent. However, for these very reasons, and given the remaining unresolved issues discussed in previous sections e.g. those relating to privacy concerns of specific groups in the community, it may be appropriate to further extend the opt out period while 'refreshing' and continuing extensive community (and clinician) education campaigns during the extended opt-out period.

Recommendations

From the points made in this submission, we have extracted the following recommendations for the consideration of the Committee:

- Comparable 'provider readiness' incentives to what are currently provided to GPs (i.e. the Practice Incentives Program e-health incentive) should also be provided to hospital and community-based specialist physicians to sign up and participate in the MHR.

- The MHR 'default' should be automatically shifted to the control of the young person once they turn 14, with no obligation for parental access.

- Marginalised and vulnerable populations such as those with sensitive diagnoses (such as HIV and mental health issues), people who use drugs, sex workers and victims of domestic violence are at risk of having their employment and other opportunities compromised in the event of a privacy breach. The Committee should consider how the privacy protections for this group can be strengthened.

- The Data Governance Board should develop appropriate principles and data governance arrangements for data pertaining to Aboriginal and Torres Strait Islander people and communities in collaboration with national Aboriginal community representative bodies such as the National Aboriginal Community Controlled Health Organisation (NACCHO) and State and Territory-based Affiliates of NACCHO, and Torres Strait Islander specific authorities. Where possible, secondary use of data pertaining to Aboriginal peoples and Torres Strait Islanders should require approval from Aboriginal HRECs (Human Research Ethics Committees).

- A renewed and well-resourced education campaign aimed at both the community and clinicians should be undertaken in the following areas:
    - For clinicians:
        - The new responsibilities they have under the MHR to ensure that it is up to date and to have appropriate conversations with their patients to supplement any gaps in the MHR as required.
        - Their responsibilities to have conversations with their patients about any sensitive diagnoses and test results before sensitive data is uploaded into the MHR and to help their patients understand and interpret these results when they are available online for viewing.
        - The distinction between using MHR for its primary purpose — providing health care to an individual patient — and all other purposes, which are secondary and education on the Framework for appropriate secondary uses.
    - For patients
        - Their new rights under the MHR and how to exercise these rights and responsibilities such as the use of access controls, the right to opt out of the system and new privacy protections being introduced.
        - The benefits of secondary use of their deidentified data for research, planning and policy purposes.

- The opt-out period should be further extended until the above issues have been appropriately addressed.

- For the next stage in the evolution of the MHR, the government should request that the Australian Digital Health Agency investigate how the MHR can be used to provide customised advice both to patients and their physicians (for instance in the form of approved clinical guidelines and other recommendations from medical colleges).

- There should be an on-going review and evaluation of both process and outcomes, and public and professional engagement relating to the rollout of the MHR and its associated public education campaigns.

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[6] RACP Submission: Federal Government Review of the Personally Controlled Electronic Health Records Program, November 2013.
[7] Productivity Commission Supporting Paper No. 5 – Integrated Care in Productivity Commission, Shifting the Dial: 5 Year Productivity Review, Inquiry Report.
[8] https://www.myhealthrecord.gov.au/sites/g/files/net5181/f/my_health_record_dashboard_-_2_september_2018_3.pdf?v=1536128283
[9] My Health Records Amendment (Strengthening Privacy) Bill 2018 Second Reading Bill, http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22chamber%2Fhansardr%2F8476f2bd-f956-415f-ae14-0f9718751478%2F0011%22
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[13] Framework to guide the secondary use of My Health Record system data May 2018.
[14] RACP Submission: Federal Government Review of the Personally Controlled Electronic Health Records Program, November 2013.
[15] RACP Submission: Federal Government Review of the Personally Controlled Electronic Health Records Program, November 2013, p.11.