

14 September 2018

Senate Community Affairs References Committee – My Health Record system

Thank you for the opportunity to make a submission into the inquiry in the My Health Record system.

AMA (NSW) is an independent organisation, which represents almost 9000 doctors-in-training, career medical officers, staff specialists, visiting medical officers, specialists and general practitioners in private practice in NSW. As the state's peak medico-political lobbying body, AMA (NSW) serves to represent the interests of its members and plays a pivotal role in the formation of health policy.

We also serve to uphold the integrity and honour of the profession and support the interests of doctors and their patients for the advancement of the health of the community.

AMA (NSW) commends the Senate Community Affairs References Committee for examining the My Health Record system.

AMA (NSW) notes the Terms of Reference, which include:

- a. the expected benefits of the My Health Record system;
- b. the decision to shift from opt-in to opt-out;
- c. privacy and security, including concerns regarding:
  - i. the vulnerability of the system to unauthorised access,
  - ii. the arrangements for third party access by law enforcement, government agencies, researchers and commercial interests, and
  - iii. arrangements to exclude third party access arrangements to include any other party, including health or life insurers;
- d. the Government's administration of the My Health Record system roll-out, including:
  - i. the public information campaign, and
  - ii. the prevalence of 'informed consent' amongst users;
- e. measures that are necessary to address community privacy concerns in the My Health Record system;
- f. how My Health Record compares to alternative systems of digitising health records internationally; and
- g. any other matters.

Further to the Terms of Reference, AMA (NSW) considers that there are 3 main domains.

1. The utility of My Health Record
2. The security of My Health Record

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### 3. The Privacy of information in My Health Record – especially pertaining to use of data

Each has specific considerations, with trust in the system by both patients and providers being paramount.

#### **BENEFITS**

AMA (NSW) strongly supports the formation of a central digital repository of patient health information, which would give authorised health providers access to relevant clinical information as and when it is needed. Patient safety and quality of care can be enhanced if treating doctors can quickly and easily access reliable, accurate patient information.

The Australian health system consists of multiple silos of service delivery, with the gaps between being an inherent risk to patient safety. Essential elements of quality care include comprehensiveness, co-ordination and continuity, with continuity of care having three elements – continuity of information, continuity of relationship, and continuity of management.

A digital platform allows better coordination of patient care across healthcare settings, by enabling informational continuity. When health providers have access to the same set of patient information, they can avoid ordering duplicate tests, prescribing contraindicated medications, prescribe more effective treatments, thus reducing waste and improving continuity of management.

The My Health Record system also enables patients to view their own health information online. Improving patient access to their own clinical data has the potential benefit of improving health literacy and patient activation, enabling patients to become more active participants in their own health care by reducing information asymmetry. Improved patient activation has been independently demonstrated to reduce health costs.<sup>i,ii</sup>

Despite the potential benefits of creating a digital repository of summarised patient information, there remains significant diversity of opinion from doctors on the current framework of the My Health Record system and its implementation thus far. There is great variation in the depth and extent of understanding of the system amongst many practitioners, particularly non-General Practice Specialists.

There is also considerable misinformation and a more general lack awareness amongst patients about what information is included in the My Health Record system, the level of security and privacy, and the patient controls within the system. In its current form, it is by no means a complete clinical record. It may not include every interaction a patient has had with the health system or an up-to-date status of their health.

The My Health Record is a summary of a patient's health information.

The *My Health Records Act 2012* authorises healthcare providers to upload information to the My Health Record System, and view information in the system. We understand that the principle of enduring consent applies, and healthcare providers do not need to obtain specific consent prior to uploading information to a My Health Record when providing services to a

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healthcare consumer. We also note views expressed by the OAIC recommending that it is good policy to obtain consent prior to each interaction with My Health Record.<sup>iii</sup> Consumers can request that a particular document is not uploaded to their record and are able to control the visibility of documents within My Health Record.

Having an electronic record system that is patient-controlled could lead to omissions in relevant information, which undermines the utility of the record. Patients must weigh the risks versus benefits of excluding information that could impact clinical decisions and outcomes. Not all patients will make a good judgement on what they should or should not include. A lack of content and limitations in accuracy compromise the usefulness of the record.

Notwithstanding the risks of a patient-controlled system, AMA (NSW) recognises patients have a fundamental right to control what information appears on their individual health record, and who can access it.

### **OPT IN VS OPT OUT**

A digital health record system, which will facilitate the communication and sharing of medical information on behalf of patients, provides the greatest potential benefit Australians who need coordinated care, or who face significant barriers to health service engagement, such as Australians with chronic and complex illnesses, Aboriginal and Torres Strait Islander People, older Australians, rural and regional residents, and people with mental illness.

While the capability for clinical information has existed for several years, the current opt-in My Health Record system has a relatively small number of registered users, with approximately 6 million Australians using the system, according to the Australian Digital Health Agency (ADHA). AMA (NSW) recognises that the utility of the system will be significantly improved by greater usage and adoption. The opt-out mechanism will make the My Health Record system much more universal, which would potentially create the critical mass of users required for the system to become a useful healthcare tool on an everyday basis. The low volume of patient information in the system currently – in terms of both patient numbers as well as volume of information – means that health providers are not in the habit of using it.

The decision to make the My Health Record an opt-out system has faced vocal opposition, with some groups arguing this process is not aligned with global best practice for informed consent, or with the Federal privacy regulator's guidelines on consent for use of health information.

Not all patients have digital access or sufficient computer or health literacy to exercise their right to opt-out of the My Health Record. Patients may be unaware of the default settings of their record, which are set on the lowest privacy setting for the widest sharing of your health information. In order to manage their privacy and security patients must log in and set access codes. Not all Australians will understand how to complete this function.

Under the current system, once a record is activated by a healthcare provider two years of Medicare Benefits Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS) data is uploaded. The patient does not have the choice to keep that data being logged unless the patient accesses the record first and decides not to upload this data. Prescription information could imply specific diagnoses a consumer would otherwise prevent from being uploaded. For example, the prescription and dispensation of antidepressants or antipsychotic drugs may imply a psychiatric diagnosis, even though these medications may be prescribed for completely different conditions. While a consumer could request their healthcare provider to not upload

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specific data or diagnoses to their My Health Record, that's not an option for past MBS and PBS data.

Despite these concerns, AMA (NSW) supports making the My Health Record system opt-out, as there remain overall benefits for individual patients and the system represents a substantial enhancement to what is currently in place. However, in making the system opt-out, the Federal Government has an even greater responsibility to ensure the legislative framework of the system is significantly tightened to allay public concerns of the system's privacy and security controls and ensure trust in the system. The principle of informed and specific consent to the use and disclosure of health data should be maintained.

In addition, the Federal Government has an obligation to conduct a wider public information campaign about the My Health Record system, and the personal controls available to users before the extended opt-out period closes. AMA (NSW) recommends the Australian Digital Health Authority sets targets for consumer engagement and understanding and reports on both measures.

### **PRIVACY AND SECURITY**

AMA (NSW) considers Security and Privacy to be two distinct domains, with quite separate controls and requirements. Nevertheless, AMA (NSW) also considers that trust by both patients and providers remains a paramount requirement.

Serious data breaches such as the cyber-attack on the Singapore Government's health database and problems with release of MBS/PBS health records in Australia reinforce the need for the Federal Government to provide Australians with assurance that the privacy and security protections of the My Health Record are watertight and will be continually improved.

The AMA has always been protective and vigilant about the privacy of the doctor-patient relationship. It is paramount that this trusted relationship is not be undermined by My Health Record.

There is considerable concern among AMA members that the current legislative framework for My Health Record fails to adequately protect the use of a person's health information and is not aligned with community expectations of privacy, and current use of health data.

The My Health Records Act currently allows the system operator, the Australian Digital Health Agency, to use or disclose information for a range of reasons unrelated to a person's health.

In the original legislation, Section 70 of the Act, states:

The System Operator is authorised to use or disclose health information included in a healthcare recipient's My Health Record if the System Operator reasonably believes that the use or disclosure is reasonably necessary for one or more of the following things done by, or on behalf of, an enforcement body:

- (a) the prevention, detection, investigation, prosecution or punishment of criminal offences, breaches of a law imposing a penalty or sanction or breaches of a prescribed law;
- (b) the enforcement of laws relating to the confiscation of the proceeds of crime;
- (c) the protection of the public revenue;
- (d) the prevention, detection, investigation or remedying of seriously improper conduct or prescribed conduct;

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(e) the preparation for, or conduct of, proceedings before any court or tribunal, or implementation of the orders of a court or tribunal.<sup>iv</sup>

The legislation could result in the release of My Health Record data to government agencies in circumstances unrelated to a person's healthcare, including for reasons relating to social security, tax and the criminal justice system.

AMA (NSW) suggests this should only be done with the patient's consent, or by court order or subpoena.

AMA (NSW) acknowledges Health Minister Greg Hunt's stated commitment to redraft the legislation. Our organisation considers this change necessary to alleviate patients' and doctors' concerns with the present system.

AMA (NSW) recognises the My Health Record data will be both valuable and useful for a wide range of secondary uses. The data is an important asset offering insight into health service utilisation across primary and tertiary sectors.

It has potential to reveal trends in health conditions; identify patients who might benefit from participation in new drug trials; or patients who might be adversely affected by TGA initiated drug or prostheses recalls. Given these potential uses, the data will be of interest to health researchers, government and commercial entities in the health sector. This is especially as My Health Record represents an aggregation of matched and identified data from different sources which would not otherwise be easily accessible in a single location.

The capacity to match PBS, Medication dispense and prescription data, along with MBS data showing locations, providers and services provided with clinical data including specific diagnoses and text fields in event summaries from multiple sources allows a richer data set than is currently easily accessible. Our members are acutely aware of the importance of protecting the privacy of patient health data. AMA (NSW) supports the statements made in Federal AMA's submission on secondary use of My Health Record data<sup>v</sup>, which states it is "vital that de-identified health data is protected from re-identification, misuse or personal gain by individuals or organisations with vested interests – commercial or criminal."

As stated in the Federal AMA's position statement, AMA (NSW) also considers the "use, disclosure and linkage of data held in the My Health Record database must be limited to research that exclusively aims to improve the health of patients, health policy analysis, health service program development and delivery, best practice health care, public health initiatives and the identification of unmet health service demand. The AMA is opposed to using My Health Record data for the purpose of improved 'safety and quality' of healthcare while-ever this label continues to be used by the Commonwealth to justify funding cuts to our already chronically underfunded public hospitals. Overall, My Health Record data should only be disclosed if the privacy risk has been minimized. It should not be used for compliance or audit purposes – the Professional Services Review is the appropriate mechanism for this."

As stated in the Federal AMA submission, My Health Record data should never be used:

- i. To monitor, interfere with or control doctor's clinical decision making;
- ii. To limit or determine doctor's remuneration;
- iii. To enable performance management of individual doctors;
- iv. To establish pay-for-performance systems;
- v. To serve vested commercial interests - including health insurers, pharmaceutical companies, and device manufacturers;

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- vi. In a way that allows sensitive health data that has been de-identified and disclosed in one setting to become re-identifiable in a different data environment.<sup>vi</sup>

AMA (NSW) also strongly recommends that My Health Record data should never be released for commercial purposes either immediate or for future use.

The current My Health Record Act 2012 does not meet AMA (NSW)'s standards of patient privacy. Under the current framework, AMA (NSW) does not support the My Health Record system.

### **ADMINISTRATION OF MY HEALTH RECORD SYSTEM ROLL OUT**

AMA (NSW) acknowledges and supports the Federal Government's decision to extend the opt-out period to 15 November 2018.

The public debate that followed from the Government's announcement of the start of the opt-out period in July is indicative of the reservations both doctors and patients have of the My Health System's current framework.

AMA (NSW) supports the adoption of the My Health Records Amendment (Strengthening Privacy) Bill 2018 to address the community's concerns regarding privacy and security of data, as well as secondary uses. Any changes to the legislation must be clearly communicated to consumers in a widely broadcast public information campaign.

AMA (NSW) also recommends the Federal Government continue a consumer engagement campaign that focuses not just on awareness, but on educating patients on use of the privacy controls built into the system before the opt-out period closes.

In order to gauge the effectiveness of this public information campaign, AMA (NSW) suggests the Australian Digital Health Authority sets targets for consumer engagement and levels of understanding and reports on both measures.

The clear variation in depth and extent of knowledge of My Health Record by providers is also of concern. AMA (NSW) suggests that a formal education campaign be implemented for all health professionals and especially non-General Practice Specialists.

Lastly, AMA (NSW) supports a public information campaign that focuses on the benefits of My Health Record, while addressing privacy and security concerns of the public. My Health Record has the potential to improve health care, but it will not "save lives". At best, overblown justifications for My Health Record raise scepticism among medical professionals and patients, and at worst, these statements undermine trust.

### **OTHER MEASURES TO ADDRESS COMMUNITY PRIVACY CONCERNS**

AMA (NSW) also recognises the Federal Government's commitment to delete records. At present, once a patient's My Health Record is created and data is uploaded onto the system, it can never be completely deleted. Amending the legislation to allow patients to completely

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delete their My Health Record gives patients reassurance that they have ultimate control over what happens to their health data now and into the future.

## **COMPARISON TO INTERNATIONAL ELECTRONIC HEALTH RECORD SYSTEMS**

There is some comparison to be made between the privacy protections of My Health Record and the EU Data Protection Reforms.

As of May 2018, the European Union implemented stronger rules on data protection. The EU Data Protection Reforms gives citizens more control over their personal data. It also provides more rights to citizens to be better informed about the use of their personal data and gives clearer responsibilities to people and entities using their personal data. Under the reforms, EU citizens have a right to:

- receive clear and understandable information about who is processing their personal data, what data they are processing and why they are processing it;
- request access to the personal data an organisation has about them;
- request one service provider to transmit personal data to another service provider;
- ask to have their personal data deleted.

The new reforms also give better protection to children online.<sup>vii</sup>

A key element of the reforms is consent. Patient health data (personal data related to the physical or mental health of a person, including the provision of health care services, which reveal information about his or her health status) and genetic data (personal data relating to the “inherited or acquired genetic characteristics of a person which give unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample”) are considered ‘sensitive data’.

The reforms prohibit sharing sensitive data, including patients’ health and genetic data, unless:

- the patient gives explicit and unambiguous consent to the use of their data
- the patient makes the data manifest himself or herself
- it is in the patient’s vital interest
- it is for healthcare purposes
- it is for public interest in the area of public health
- it is to carry out the right of the person that controls patients’ data in the field of employment, social security and social protection law
- it is in substantial public interest
- it is for other more specific reasons
- Processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes<sup>viii</sup>

The new regulations establish rules to strengthen citizen’s rights over the process of consent for the collection, use and sharing of their personal data. The reforms give clear guidelines around consent.

Under the guidelines, consent must be explicit and unambiguous. It needs to be given through a clear affirmative act and it has to be freely given. It must be an “unambiguous indication of a data subject’s agreement to the processing of their personal data”. This can be written, electronic or oral. Silence or inactivity (a pre-ticked box for example) cannot be considered as consent.

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The guidelines also state that data controllers – persons or entities that collect data from people – have to be able to demonstrate that a person has given consent.

Consent has to be informed. It has to be in intelligible and easily accessible forms, using clear and plain language, and be distinguishable from other matters.

In addition, patients should be informed on how to withdraw consent prior to giving it.

For children below 16, parental consent is necessary for the processing of data to be lawful– Member States may decide to lower that age, but not below 13.<sup>ix</sup>

The EU Data Protection Reforms strive to take a balanced approach to protect patient’s privacy while ensuring patient data can be shared for healthcare and research purposes.

Underpinning these reforms is patient consent. AMA (NSW) suggests a similar foundation should underpin the My Health Record system, particularly in regard to secondary uses of patient data.

## **OTHER MATTERS**

AMA (NSW) is unable to qualify the lack of participation of its members in the My Health Record system, but anecdotal evidence suggests there currently exists a hesitancy to endorse and implement the My Health Record system. We suggest that concerns with the current privacy controls, as well as the variation in depth and extent of knowledge of My Health Record by providers are some of the biggest obstacles to participation among medical professionals. In addition to strengthening the privacy controls in the Act, AMA (NSW) suggests general practitioners need greater support.

AMA (NSW) recommends the Federal Government implements an appropriate incentive scheme to support general practitioners in facilitating use of My Health Record, as well as the implementation of systems and processes that ensure quality of data, while minimising the administrative burden on healthcare providers.

Yours sincerely,



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- <sup>iii</sup> <https://www.oaic.gov.au/resources/agencies-and-organisations/business-resources/privacy-business-resource-23-handling-personal-information-in-the-my-health-record-system.pdf>. (2018)
- <sup>iv</sup> *My Health Record Act 2012*, Division 2, Subdivision B, s70
- <sup>v</sup> Australian Medical Association (2017). *AMA Submission on the Framework for the secondary use of My Health Record Data*. Available at: <https://ama.com.au>.
- <sup>vi</sup> Australian Medical Association (2017). *AMA Submission on the Framework for the secondary use of My Health Record Data*. Available at: <https://ama.com.au>.
- <sup>vii</sup> European Patients Forum (2016). *EU Data Protection Reform: better data protection rights for European citizens*. [pdf]. Available at: [https://ec.europa.eu/commission/sites/beta-political/files/data-protection-factsheet-citizens\\_en.pdf](https://ec.europa.eu/commission/sites/beta-political/files/data-protection-factsheet-citizens_en.pdf)
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