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Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

By email: community.affairs.sen@aph.gov.au

Dear Sir/Madam,

We welcome the opportunity to provide feedback in relation to the Senate Standing Committees on Community Affairs References Committee's inquiry into the My Health Record system.

Please do not hesitate to contact me and my colleagues [REDACTED] if we can further assist with the Committee's important work.

Yours faithfully,

Tom Ballantyne
Principal
MAURICE BLACKBURN





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**Maurice Blackburn
submission to the My
Health Record Inquiry**

September 2018

Maurice Blackburn Lawyers submission to the inquiry into the My Health Record System.

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Maurice Blackburn Lawyers submission to the inquiry into the My Health Record System.

Introduction

Maurice Blackburn Pty Ltd is a plaintiff law firm with 31 permanent offices and 29 visiting offices throughout all mainland States and Territories. The firm specialises in personal injuries, medical negligence, employment and industrial law, dust diseases, superannuation (particularly total and permanent disability claims), negligent financial and other advice, and consumer and commercial class actions.

Maurice Blackburn employs over 1000 staff, including approximately 330 lawyers who provide advice and assistance to thousands of clients each year. The advice services are often provided free of charge as it is firm policy in many areas to give the first consultation for free. The firm also has a substantial social justice practice.

A number of Maurice Blackburn's practice areas have direct experience with issues relevant to this Inquiry. Our medical negligence practice is Australia's largest and has significant experience with the claims arising from the kinds of communication failures that the My Health Record system is designed to address. They also have experience with various privacy issues arising out of health information.

Further, our industrial and insurance practices have direct experience with privacy and related issues arising in the context of employment and insurance disputes.

Our Submission

Maurice Blackburn believes that the My Health Record system has obvious potential to improve health care outcomes.

However, we also believe there are legitimate concerns with current provisions related to access, consent and default settings. These must be tightened so patients know what they are consenting to, who is accessing records, and for what purpose.

We are concerned that undue pressure may be placed on patients to allow access to their My Health Record for employment and insurance purposes, and that the consent process enabling such access is deficient.

We are concerned about medical practitioners accessing a patient's My Health Record for these purposes without the need for specific consent from the patient.

We are concerned that the system may discourage patients from having conversations with their doctor – especially in relation to mental health issues – for fear of that information being seen by doctors performing pre-employment screening, or by those contributing to insurance decisions.

We believe there are simple adjustments that can be made to the legislation to ensure that data cannot be used improperly.

We believe that the combination of a disengaged or under informed patient base, and an opt-out system will not work. The messaging needs to encourage people to take responsibility for their My Health Record. Depending on the individual circumstances, this may take the form of:

- Opting out,
- Talking to their doctor about what does and what does not get uploaded onto the system, and
- The importance of setting their security codes and access notifications.

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Maurice Blackburn believes that, above all, communications in relation to the My Health Record system need to be comprehensive and open. It needs to recognise the benefits of the system, but also that people may have genuine reasons for opting out.

Responses to Terms of Reference

A. The expected benefits of the My Health Record system

Maurice Blackburn has been aware of the potential benefits of the My Health Records system since it was introduced by the then Labor Government in 2012.

In 2012, the *My Health Records Act* (2012) was passed, enabling the establishment for individual, on-line health care records to be held in a central on-line location on an opt-in basis.

Core to the purpose of the Act is giving patients and doctors on-line access to medical information about the patient, including test results, referral letters, organ donation status etc.

The Act¹ describes the objects of the scheme as:

“... to enable the establishment and operation of a voluntary national system for the provision of access to health information relating to recipients of healthcare, to:

- a) help overcome the fragmentation of health information; and*
- b) improve the availability and quality of health information;*
- c) reduce the occurrence of adverse medical events and the duplication of treatment; and*
- d) improve the coordination and quality of healthcare provided to healthcare recipients by different healthcare providers”.*

The stated objects provide potential benefits for patients, workers, medical practitioners, medical facilities and the wider community.

For patients, the My Health Record scheme has the capacity to be a useful document archive made up of information about the individual that is shared, with the knowledge and permission of that individual, between health care professionals.

For workers, we have direct experience of cases where the existence of My Health Record would have changed the outcome of worker's experiences with the healthcare system. For example, there is a growing problem with addiction and misuse of prescription pain killers, including following a workplace injury. My Health Record will help address this problem by ensuring health service providers are aware of the prescription history and thereby help to prevent 'doctor shopping'.

Further, workplace injuries are responsible for many ongoing, chronic physical and psychiatric injuries that require treatment by various specialties and providers. An up to date centralised source of health information like My Health Record could improve outcomes and reduce the administrative burden on injured workers.

From the perspective of medical practitioners, ready access to information uploaded by other healthcare professionals would save time, and reduce the incidence of information 'falling between the cracks' in developing a holistic picture of a patient's health.

¹ Refer <https://www.legislation.gov.au/Details/C2017C00313>, s.3

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From a societal perspective, technology is constantly changing and being incorporated into all aspects of our lives. Our relationship with technology is changing as well – we are more likely to trust technologies with our credit card details, or our residential circumstances, or our likes and dislikes. The storing and providing of access to medical records is an extension of our changing views of privacy.

We note that the AMA sees this initiative as a move away from paper-and-filing-cabinet-based, pre-historic system to something future focused.² We agree with this perspective, and believe that communication between health service providers is currently inconsistent and fractured.

In our experience, many providers still rely on outdated and unreliable technology, such as fax. We have seen numerous instances where poor communication, misplaced information or a lack of follow-up between different doctors and healthcare providers has resulted in patients suffering otherwise avoidable harm. We believe that the My Health Record scheme is well placed to help mitigate this risk and improve health outcomes.

B. The decision to shift from opt-in to opt-out

As noted above, the My Health Record system was introduced by the then Minister Roxon as an opt-in system. In November 2017 the then Minister for Health made the decision to move to an opt-out scheme.

The shift from opt-in to opt-out is central to the concerns that Maurice Blackburn has about the system. The shift heightens the need for safeguards, and raises questions about whether there might be a corresponding need to change the default settings.

Under an opt-in system, it is reasonable to assume a level of implicit agreement about the uploading of information, because there has been an active decision by the patient to opt in to the scheme. This however does not apply in an opt-out regime.

For example, the default setting for the uploading of a test result by a doctor may be set at “upload” rather than “do not upload”. Whilst this might be appropriate in an opt-in system, because the patient has made an informed decision to have their information uploaded, this is not the case for an opt-out regime.

As the process described in the Act reflects:

“If a healthcare recipient is registered in the My Health Record system, a healthcare provider may upload health information about the recipient to the My Health Record system, unless the record is one which the healthcare recipient has advised the healthcare provider not to upload...”

The default access settings also seem to provide standing consent for all registered healthcare provider organisations to access a patient My Health Record. Again, this may be appropriate in an opt-in system where consent is implicit in the act of registering. The same cannot be said of an opt-out system.

Regardless of whether the scheme is opt-in or opt-out, the important element of the process is that the healthcare recipient has the choice about what appears and does not appear in his/her My Health Record.

² <https://www.news.com.au/technology/online/security/its-time-to-decide-if-you-want-to-opt-out-of-new-my-health-record/news-story/77dc11f719eab73adcd851145cd2517a>

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C. Privacy and security

i. the vulnerability of the system to unauthorised access

We recognise that a number of safeguards have been built in to mitigate the risk of unauthorised access:

- Patients have control over what is uploaded to their My Health Record. As noted in our response to ToR B, patients have the ability to request their doctor(s) to include or not include certain records in their My Health Record.
- Patients can track what's being uploaded to their record, and who has accessed it. By logging on, healthcare recipients can:
 - Set a Record Access Code – a code they can then give only to those they want to give permission to access their records, and/or
 - Set a Limited Document Access Code, if they want to restrict access to a certain document.
- Patients can track changes to the information on the system – who has accessed information and what they've done – uploaded documents, or modified or removed documents. Patients can set up an email or SMS alert for when a healthcare organisation or professional accesses their record for the first time.

Maurice Blackburn is concerned that the instigation of the above safeguards requires a degree of awareness, literacy and understanding of the system. Once again, this is a reasonable assumption under an opt-in regime – as the healthcare recipient has made an informed decision about their participation. Under an opt-out system, a disengaged patient could inadvertently fail to set up appropriate safeguards, and not know until after information has been shared.

Maurice Blackburn believes that the best way to mitigate the risk of unauthorised access is to prioritise the need for **informed and deliberate consent**.

If the system has default settings which place the patient's consent at the centre of decision making, many concerns related to inappropriate access will be negated. For example, if the default settings were changed to require a patient's consent every time the record is accessed, it would provide a measure of protection until such time that the patient made a considered and informed decision to grant standing access. This would also assist in ensuring that patients engaged with the system.

Failure to have access determined by informed consent will lead to the data potentially being used for unrelated purposes. For example:

- New or prospective employees may be asked by an employer to undergo a pre-employment medical check. There may be unrelated historical data on their record (for example, a discussion several years ago between the employee and their doctor about depression) which, may impact the results of the medical check.
- A young person, under the age of eighteen, who may have had a discussion with his/her GP about sexual activity or sexually transmitted diseases may not want their parents to be privy to the fact that that conversation took place.

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- By a parent accessing a child's medical history for improper purposes. This is particularly relevant in the context of domestic violence and family law issues.

The informed and deliberate consent of the patient should form the basis of how information is uploaded to the system, and access to that information is granted.

Maurice Blackburn is particularly concerned about the potential for perpetrators of domestic violence to be able to track the location of their victims through access to information (for example, the address of doctor's clinics) on their children's My Health Record. We encourage the Committee to consider mitigations for this form of unauthorised access as a matter of urgency.

ii. the arrangements for third party access by law enforcement, government

Maurice Blackburn is concerned by the lack of certainty that seems to exist around whether information can be accessed from My Health Records without the need for a warrant, subpoena or court order.³

Maurice Blackburn notes that giving law enforcement or government departments unfettered access to health information has the potential to seriously jeopardise the relationship between patient and healthcare professional.

Maurice Blackburn agrees there will be certain, rare situations where it may be appropriate for law enforcement or government to access the information contained within My Health Records, but supports the argument that this information should be legally protected from access by law enforcement/government to at least the same degree as currently exists for records held by a doctor.

iii. agencies, researchers and commercial interests

Maurice Blackburn notes that the legislation allows for industry level, de-identified information to be provided for the purposes of research. As the Health Department's website says:

*"In addition to supporting your care, the data in the My Health Record system may also be used to provide insight into the effectiveness of the services and treatments being provided to continue to improve health outcomes. This data will help health researchers and public health experts ensure patients receive evidence-based care and that future health investment is directed at those who need it most."*⁴

Maurice Blackburn further notes that significant community concerns have been expressed about the degree to which de-identifying data actually protects individual privacy.

Maurice Blackburn encourages the Committee to satisfy itself that appropriate safeguards exist to ensure that this data cannot be used for commercial purposes.

³ See for example <https://www.theguardian.com/australia-news/2018/jul/25/police-can-access-my-health-record-without-court-order-parliamentary-library-warns>

⁴ <http://www.health.gov.au/internet/main/publishing.nsf/Content/eHealth-framework>

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

Our reasons for concern in this regard are directly connected to our day to day work.

Insurers, particularly those that offer life insurance, regularly put pressure on applicants to provide access to medical information.

This raises a number of concerns for several cohorts, including:

- **Employees who are injured at work and are seeking compensation** – already, in our experience, insurers can be very aggressive in the use of and in seeking to access records to deny someone compensation when such information is not relevant. We fear this could be exacerbated with greater unfettered access for insurers where consent is not clear;
- **Those seeking to access insurance through their superannuation** - who similarly may be put at a disadvantage in having their insurance claims denied because an insurer has access to their full record, and has used something historical and irrelevant to deny a claim; and
- **Those with mental health issues seeking insurance** – the Royal Commission Misconduct in the Banking, Superannuation and Financial Services has recently heard many examples of people being excluded from gaining insurance or having claims denied due to blanket mental health exclusions. We are concerned people may be disinclined to discuss mental health concerns if they feel this could be brought up later and used against them, even in the absence of an official diagnosis.
- **Those at risk of discrimination in the employment context** – there is clear risk that unfettered access to a patient's medical history could lead to discrimination in the employment process due to a pre-existing health condition.

While many of these concerns apply equally to the disclosure of records from individual healthcare providers before the scheme existed, the My Health Record system is unique in that it potentially allows access to a patient's entire health and treatment history, regardless of relevance and sensitivity.

Maurice Blackburn, along with our union colleagues have been vocal about these potential unintended consequences of the My Health Record system⁵. We believe that the consent process surround access to My Health Record for these purposes must be detailed and robust. Patients must understand what records are in the system and what the health practitioner will be looking at.

As discussed earlier, Maurice Blackburn is also concerned that medical practitioners engaged by employers or insurers may be able to access patient's My Health Record without notice to the patient or any additional consent process.

Our interpretation of the legislation suggests that a health assessment by a medical practitioner for these purposes falls within the definition which allows access to My Health

⁵ See, for example, <https://www.theage.com.au/business/workplace/unions-urge-members-to-opt-out-of-myhealth-record-20180806-p4zvr6.html>

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Record.⁶ Because of the 'opt out' nature of the scheme and the default settings allowing standing access to providers for certain purposes, patients may not even realise that their My Health Record is being accessed.

Government departments maintain that these fears are unjustified, as access for these purposes is prohibited by s.14(2) of the *Healthcare Identifiers Act* 2010, which states that it is illegal to use the Healthcare Identifier of a patient to access health information for purpose of communicating or disclosing health information for purpose of:

1. underwriting a contract of insurance that covers the healthcare recipient; or
2. determining whether to enter into a contract of insurance that covers the healthcare recipient (whether alone or as a member of a class); or
3. determining whether a contract of insurance covers the healthcare recipient in relation to a particular event; or
4. employing the healthcare recipient.

Our reading of this section is that the protection will only apply if a provider accesses medical records for these purposes using a patient's Healthcare Identifier. While there may be alternative interpretations, this appears to be the most obvious.

The key question then becomes whether a provider needs to use a patient's Healthcare Identifier to access the medical records stored in My Health Record. The Government has argued that they do, so the above protections must apply.

However, in Maurice Blackburn's opinion, it appears that a patient's My Health Record can be accessed without using their Healthcare Identifier.

In the provider portal⁷, to search for a particular patient's My Health Record, a healthcare worker would need to enter the patient's surname, date of birth, sex and then one of their Healthcare Identifier, Medicare number or DVA file number.

From our research, it appears that Healthcare Identifier, Medicare and DVA numbers are all distinct identifiers. On that basis, if a doctor were to access a My Health Record via a Medicare number or a DVA file number, the protections provided by s.14(2) would not apply.

It must be acknowledged that there can be alternative interpretations of the legislation, or additional protections that may prevent access for these purposes. However, we believe that this is the most accurate interpretation and have been unable to identify any additional protections.

Potential Solutions:

We agree that the four exclusions listed in S.14 (2) of the *Healthcare Identifiers Act* 2010, as listed above, represent adequate provisions for the protection of workers' health data if they applied to all attempts to access of a patient's My Health Record. However, there must be much greater clarity as to whether this is actually the case.

This could be done by:

- Adding a clause similar to S.14(2) to the My Health Record Act 2012, or

⁶ See s.5 *My Health Records Act* 2012 and s.6 *Privacy Act* 1988.

⁷ <https://www.digitalhealth.gov.au/files/assets/cup-articulate/using-the-provider-portal/providerPortal/index.html>

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- Tightening the means for accessing the My Health Record, as set out in the Act, to ONLY be permitted via the use of the patient's Healthcare Identifier.

The first option is relatively simple and would obviously remove any doubt about the prohibition on accessing My Health Record for those specific purposes without specific consent. If the Government agrees that My Health Record should not be used for these purposes, then this is the most obvious solution.

We foresee that the second option could be more problematic, as the Healthcare Identifier is not commonly used by patients – compared to, say, the Medicare number. Minister Hunt in his second reading speech said:

*“The My Health Record system will improve health outcomes by providing important health information when and where it is needed so that the right treatment can be delivered safer and faster. **It enables individual consumers to access all their own individual healthcare records privately and securely for the first time**”.*⁸

Restricting access requirements to only permitting access with the use of a Healthcare Identifier may make it difficult for ‘individual consumers to access all their own individual healthcare records privately and securely’, as most would not know their Healthcare Identifier.

Regardless of the methodology used to tighten access to My Health Record data, Maurice Blackburn submits that it is vitally important to ensure that the consequences for misuse are clearly spelled out in the My Health Record act.

We believe that the owner of the My Health Record platform should have overall responsibility for the appropriate usage of the data held in the system.

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

- v. the public information campaign, and
- vi. the prevalence of ‘informed consent’ amongst users;

Please refer to our response to Terms of Reference B and C (i) in relation to ‘informed and deliberate consent’.

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

Maurice Blackburn believes there are two important elements to address community privacy concerns: fixing the legislation, and fixing the communications.

The Legislative fix

For our suggestions on the most appropriate adjustments to the relevant legislation, please refer to our section entitled “Potential Solutions”, as part of our response to Term of Reference C.

The Communications Fix

⁸ HoR Hansard, Wednesday, 22 August 2018. p.6

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Aside from the issues relating to communications around safeguards, the Government needs to convince people that they can be trusted with personal data.

This will not be an easy task, particularly given recent information technology and security breaches.⁹

Health data is an attractive target for hackers. The community will be seeking reassurances that government processes have this risk under control. This is not easy when the former head of the Digital Transformation Agency has expressed concerns.¹⁰

Maurice Blackburn believes that, above all, communications in relation to the My health Record system need to be truthful. It needs to recognise the benefits of the system, but also that people may have genuine reasons for opting out.

As noted above, the combination of a disengaged patient base, and an opt-out system will not work. The messaging needs to encourage people to take responsibility for their My Health Record.

Depending on the individual circumstances, this may take the form of:

- Opting out,
- Talking to their doctor about what does and what does not get uploaded onto the system, and
- The importance of setting their security codes and access notifications.

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

No response to this term or reference.

G. Any other matters

No response to this term or reference.

⁹ See, for example <https://www.smh.com.au/technology/medicare-details-of-every-australian-currently-up-for-sale-on-the-dark-web-20170704-gx40ow.html>, or <https://www.smh.com.au/technology/revealed-serious-flaws-in-mygov-site-exposed-millions-of-australians-private-information-20140514-zrczw.html>

¹⁰ <http://www.abc.net.au/news/2018-07-18/my-health-record-former-digital-transformation-boss-has-concerns/10006788>