

Submission to the Senate Community Affairs References Committee Inquiry into the My Health Records System

September 2018

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1 PRELIMINARY SUMMARY

1. The ETU is not ideologically opposed to the overarching policy principle of the My Health Records system.
2. The conversion of My Health Records from “opt in” to “opt out” was poorly planned, poorly communicated and poorly implemented.
3. The legislation provides no protection for workers information being accessed by employer or insurer nominated health practitioners.
4. The legislation places no positive obligation on the digital platform or on the owner of the digital platform to ensure it can only be used in the way the legislation permits.
5. The legislation allows for health information recorded in the My Health Report to be permitted to be passed on for “secondary use purposes” under control of a Governance Board not yet established.
6. The ETU will not support the My Health Record System while these access concerns remain and will continue to actively encourage our members to opt out until the system is fixed.

2 INTRODUCTION

The Electrical Trades Union of Australia (ETU) is the Electrical, energy and Services Division of the Communications, Electrical, Electronic, Energy, Information, Postal, Plumbing and Allied Services Union of Australia (CEPU). The ETU represents approximately 65,000 electrical and electronic workers around the country and the CEPU as a whole represents approximately 100,000 workers nationally, making us one of the largest trade unions in Australia.

The ETU welcomes the opportunity to make a submission to the Senate Community Affairs References Committee Inquiry into the My Health Records system. It is important to place clearly on the record that the ETU is not ideologically opposed to the overarching policy principle of the My Health Records system.

While it is clear that My Health Record could have the potential to improve health care and outcomes, there are also legitimate concerns with access provisions. These must be tightened so patients and doctors know what they are consenting to, who is accessing records, and for what purpose. This is particularly important in the context of health assessments for employment and insurance purposes.

Regrettably, the poor implementation of the system, the lack of public engagement and consultation on the change from opt in to opt out and the serious deficiencies in access arrangements renders the system unacceptable in its current state.

3 DEFAULT SETTINGS PROVIDE ACCESS FOR EMPLOYMENT PURPOSES

The Australian Digital Health Agency (ADHA) has asserted that it does not consider that an employment check is healthcare, however, nothing in the legislation, rules or other material supports their position. Indeed, the legislation behind My Health Record directly contradicts the Agency's position as set out below (emphasis added);

MY HEALTH RECORDS ACT 2012 - SECT 61 Collection, use and disclosure for providing healthcare

MY HEALTH RECORDS ACT 2012 - SECT 61¹

Collection, use and disclosure for providing healthcare

(1) A participant in the [My Health Record system](#) is authorised to collect, use and disclose [health information](#) included in a [registered healthcare recipient's My Health Record](#) if the collection, use or disclosure of the [health information](#) is:

(a) for the purpose of [providing healthcare to the registered healthcare recipient](#); and

(b) in accordance with:

(i) the [access controls set](#) by the [registered healthcare recipient](#); or

(ii) if the [registered healthcare recipient](#) has not set access controls--the default access controls specified by the My Health Records Rules or, if the My Health Records Rules do not specify default access controls, by the [System Operator](#).

MY HEALTH RECORDS ACT 2012 - SECT 5 Definitions²

MY HEALTH RECORDS ACT 2012 - SECT 5

Definitions

"healthcare" means health service within the meaning of [subsection 6\(1\)](#) of the [Privacy Act 1988](#).

PRIVACY ACT 1988 - SECT 6FB Meaning of health service³

PRIVACY ACT 1988 - SECT 6FB

Meaning of health service

(1) An activity performed in relation to an [individual](#) is a [health service](#) if the activity is intended or claimed (expressly or otherwise) by the [individual](#) or the person performing it:

(a) [to assess](#), maintain or improve the [individual's](#) health; or

(b) where the [individual's](#) health cannot be maintained or improved--to manage the [individual's](#) health; or

(c) to [diagnose the individual's illness, disability or injury](#); or

(d) to treat the [individual's](#) illness, disability or injury or suspected illness, disability or injury; or

(e) to [record the individual's health for the purposes of assessing, maintaining, improving or managing the individual's health](#).

So a provider can assess, diagnose and record information subject to the "access controls" set by the user. This is where the issue of default settings comes into play.

¹ [My Health Records Act – Collection Use and Disclosure](#)

² [My Health Records Act - Definitions](#)

³ [Privacy Act – Meaning of Health Service](#)

Default Settings of MyHealth Report

<https://www.myhealthrecord.gov.au/for-healthcare-professionals/patient-access-controls>

How is consent managed in the My Health Record system?

By default, when an individual registers for a My Health Record they give standing consent for all registered healthcare provider organisations to access and upload information to their My Health Record. Healthcare professionals working in healthcare provider organisations can:

- Access the individual's My Health Record during, or in regard to, a consultation or clinical event involving the individual; and
- [View all documents in the My Health Record system](#) and upload documents to the My Health Record, unless the individual specifically requests the healthcare professional not to upload the document.

A meeting was held between the ETU and the ADHA on Friday 6 July 2018 in Melbourne and it was confirmed at that meeting by two ADHA representatives that the ETU's interpretation was correct.

By way of specific example, a My Health Record of a worker (whose My Health Record was left at the default setting) can be accessed by a registered health practitioner, performing a pre-employment medical assessment or workers compensation injury assessment on behalf of an employer. Further, there is no penalty or recourse for this taking place nor is there any way the My Health Record system can prevent this from occurring.

The ETU has repeatedly requested evidence to the contrary outlining the particular provision of the legislation that forbids this form of access including the penalty provision associated with a breach of that provision and how the application of the My Health Record platform supports this.

4 SECONDARY USE PURPOSES

Under the My Health Record system, information recorded in the system is permitted to be passed on for "secondary use purposes" under control of a Governance Board not yet established. These purposes are entirely unclear, and in particular, the ETU has concerns that the rules surrounding the Governance Board are also unclear.

It is completely unacceptable that Australian's will have a record created which may be accessed by third parties under rules and standards not yet established.

The legislation also allows for the Minister of the day to delegate to any person of their choosing the capacity to access and interrogate the information contained in the My Health Record System including health recipients information.

Further, the potential for this Government or future Governments to privatise the digital platforms and databases which manage the My Health Record is something that would not be supported by a majority of Australian Voters. The legislation should contain a mechanism which prevents the privatisation of the My health Record without a two thirds majority vote in both houses.

Finally, access for law enforcement purposes needs clarification and strengthening. The reasons for access must be narrow, clearly articulated and completely transparent with agencies only able to access via a court order and the health care recipient being notified of the access unless the court determines otherwise.

5 NO-ONE KNOWS ABOUT IT

It is deeply concerning that such a large social program could be enacted with close to no community and public engagement. Most Australians have little to no understanding about what the My health Record System is, who administers is, for what purpose and how they, as health care recipients, can control and monitor their own records.

Even those that have taken an interest in this program regularly report that the system is extraordinarily difficult to navigate, the security settings are not straight forward, and the information retained is not easily understood.

The Government has completely failed to establish a credible “social licence” to pursue its current course of action. That is not to say that it couldn’t, but it is extremely poor public policy to implement a program and then consult afterwards in the hope of achieving public support.

Resources must be allocated to increase the awareness and competence of the general public in interreacting with and controlling their My Health Record as a matter of urgency.

6 CASE STUDIES

Case Study 1 – Pre Employment

Jill is supervisor who 5 years ago, needed to take 6 weeks off for “stress” that was approved by her private doctor. The doctor also prescribed some medication for Jill that is commonly associated with the treatment of mild depression. Jill took the medication with resolution of her symptoms.

Jill returned to work following her treatment and has worked very successfully ever since, recently relocating to a new division within the company.

Jill is looking to progress her career and is applying for a promotion to Manager in the company which requires she attend a medical assessment. The company has a preferred medical practitioner arrangement and the employer’s letter to practitioner performing the assessment is asked to assess her capacity to deal with a range of scenarios including erratic work volumes, difficult meetings, manage difficult stakeholders and complex client relationships and ask the practitioner to express a view on her capacity to perform the inherent requirements of the new role.

Jane has a great resume and impressed in the interviews and the company is on the verge of hiring her.

The company doctor sees that Jill has been prescribed depression medication as part of her digital My Health Record and in the report to the company notes a “risk” of her capacity to perform the inherent requirements of the role. The company then decide not to hire Jill.

Case Study 2 – Employment

Five years ago John went through a period of using illicit drugs on the weekends. There was no impact on his workplace performance. He eventually decided to stop using and sought help from a doctor who prescribed medication as part of a rehabilitation program which John successfully completed and has been ‘clean’ ever since. John works in construction industry which, under the building code, requires a drug and alcohol policy which requires an annual medical for high risk workers focussed on illicit substance use.

John attends his annual medical provided and paid for by his employer. John’s medical history on his My Health Record includes medication related to his recovery treatment and is made known to the employer by the doctor. The employer has flagged John for increased drug tests at work as a result and will keep a close eye on his performance and behaviour.

Case Study 3 – Workers Compensation

Sally applies for a job with a local church run support centre. Part of the pre-employment process requires her to attend a pre-employment medical at a practitioner nominated by the church. The medical practitioner is a member of the church and is close friends with the Bishop due to their work together at university campaigning against reproductive rights.

As part of the pre-employment medical assessment, the Dr accesses Sally’s My Health Record and notices that she underwent a termination of pregnancy procedure 2 years earlier. He calls his friend the Bishop later that evening and tells him about the procedure.

Sally is notified later that week that her application was unsuccessful at this time, no further reason is given.

7 RECOMMENDATIONS

As stated at the beginning of our submission, the ETU acknowledges that the MHR system can bring real benefits to Australians both as patients and workers in the health system. The issues we have outlined are not arguments against the system being implemented, but instead, is a list of issues that must be addressed to provide comfort to citizens.

Recommendation 1

The default setting for access to a My Health Record must be one of no access for employment matters and the rules and legislation must support this position by providing for penalties and placing a positive obligation on the digital platform and its owner to ensure the system prevents this form of access.

Recommendation 2

Directly including a clause similar to s14(2) *Healthcare Identifiers Act 2010*'s (Cth) into the MHR Act that excludes access for the purposes described in that clause. The exclusion should clearly apply irrespective of how the MHR is accessed (i.e. using a IHI or Medicare number, etc) and also cover access during employment and not just recruitment. Some allowance has to be made for the sharing of information based on consent from the patient, but consent needs to be clearly delineated in the legislation and needs to rely on clear, informed consent of what the patient is agreeing to. Consent also needs to be purpose-based and be considered to expire when the purpose does.

Recommendation 3

Access for enforcement bodies' should only include crime enforcement agencies seeking access for the purpose of investigating crime and authorisation should require a court order. The patient should be notified that the record has been accessed unless the court determines otherwise.

Recommendation 4

Non-compliance with MHR requirements around privacy must include significant penalties for both organisations and individuals.

Recommendation 5

Legislative obligations around data security, privacy and probity must also apply to the holder of the database, not just those accessing it.

Recommendation 6

The ADHA must be tasked with improving access to the My Health Record through clearer and easier to use controls over data upload.

Recommendation 7

The Government must allocate better resources to take measures that increase the awareness of and uptake of increased privacy settings for those who have been automatically opted-in and evidence shows they have not attempted to access their record or account.

Recommendation 8

Legislative safeguards must be implemented against privatisation or commercialisation of the database and the overarching rules for access by third parties must be legislated.

Recommendation 9

The section which allows for the Minister of the day to nominate any person to access information in the My Health Record System must be removed.

8 CONCLUSION

What could have been a highly beneficial health initiative has been totally undermined through poor planning and poorer implementation. The opportunity for My Health Record to improve health care and outcomes is being undermined by legitimate concerns with access provisions. These must be tightened so patients and doctors know what they are consenting to, who is accessing records, and for what purpose. This is particularly important in the context of health assessments for employment and insurance related purposes.

The public must have full confidence and awareness of the My health Record System so that they can be active and willing participants in the use and operation of it. Such an important program requires a social licence that currently doesn't exist.