



Law Council
OF AUSTRALIA

My Health Record system

Senate Standing References Committee on Community Affairs

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Telephone +61 2 6246 3788 • *Fax* +61 2 6248 0639
Email mail@lawcouncil.asn.au
GPO Box 1989, Canberra ACT 2601, DX 5719 Canberra
19 Torrens St Braddon ACT 2612
Law Council of Australia Limited ABN 85 005 260 622
www.lawcouncil.asn.au

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About the Law Council of Australia

The Law Council of Australia exists to represent the legal profession at the national level, to speak on behalf of its Constituent Bodies on national issues, and to promote the administration of justice, access to justice and general improvement of the law.

The Law Council advises governments, courts and federal agencies on ways in which the law and the justice system can be improved for the benefit of the community. The Law Council also represents the Australian legal profession overseas, and maintains close relationships with legal professional bodies throughout the world.

The Law Council was established in 1933, and represents 16 Australian State and Territory law societies and bar associations and the Law Firms Australia, which are known collectively as the Council's Constituent Bodies. The Law Council's Constituent Bodies are:

- Australian Capital Territory Bar Association
- Australian Capital Territory Law Society
- Bar Association of Queensland Inc
- Law Institute of Victoria
- Law Society of New South Wales
- Law Society of South Australia
- Law Society of Tasmania
- Law Society Northern Territory
- Law Society of Western Australia
- New South Wales Bar Association
- Northern Territory Bar Association
- Queensland Law Society
- South Australian Bar Association
- Tasmanian Bar
- Law Firms Australia
- The Victorian Bar Inc
- Western Australian Bar Association

Through this representation, the Law Council effectively acts on behalf of more than 60,000 lawyers across Australia.

The Law Council is governed by a board of 23 Directors – one from each of the constituent bodies and six elected Executive members. The Directors meet quarterly to set objectives, policy and priorities for the Law Council. Between the meetings of Directors, policies and governance responsibility for the Law Council is exercised by the elected Executive members, led by the President who normally serves a 12 month term. The Council's six Executive members are nominated and elected by the board of Directors.

Members of the 2018 Executive as at 1 January 2018 are:

- Mr Morry Bailes, President
- Mr Arthur Moses SC, President-Elect
- Mr Konrad de Kerloy, Treasurer
- Mr Tass Liveris, Executive Member
- Ms Pauline Wright, Executive Member
- Mr Geoff Bowyer, Executive Member

The Secretariat serves the Law Council nationally and is based in Canberra.

Acknowledgement

The Law Council acknowledges the assistance of its Privacy Law Committee of the Business Law Section, the Family Law Section, the Law Institute of Victoria, and the Law Society of New South Wales in the preparation of this submission.

Executive Summary

1. The Law Council welcomes the opportunity to provide this submission to the Senate Standing References Committee on Community Affairs' (**the Committee**) Inquiry into the My Health Record system (**the Inquiry**).
2. The Law Council acknowledges the Senate Community Affairs Legislation Committee's Inquiry into the My Health Records Amendment (Strengthening Privacy) Bill 2018. The Law Council's submission to that Inquiry will be provided separately.
3. This submission responds to the Inquiry's following Terms of Reference:
 - the expected benefits of the My Health Record (**MHR**) system;
 - the decision to shift from opt-in to opt-out;
 - privacy and security, including concerns regarding:
 - the vulnerability of the system to unauthorised access,
 - the arrangements for third-party access by law enforcement, government agencies, researchers and commercial interests, and
 - arrangements to exclude third-party access arrangements to include any other party, including health or life insurers;
 - the Government's administration of the MHR system roll-out, including the prevalence of 'informed consent' amongst users; and
 - how the MHR system compares to alternative systems of digitising health records internationally.
4. The Law Council makes the following recommendations in relation to the Inquiry:
 - The MHR should build on the lessons learned from Personally Controlled Electronic Health Records (**PCEHR**).
 - In relation to access by employers to medical records of employees asked to undergo a medical check:
 - consideration be given to removing or qualifying the exemption under section 7B(3) of the *Privacy Act 1988* (Cth) (**Privacy Act**); or
 - the MHR Act be amended so that there are additional privacy protections for the health records of employees when accessed by employers.
 - The use of the term 'parental responsibility' in the *My Health Record Act 2012* (Cth) (**MHR Act**) be replaced with an alternative term such as 'parental rights'.
 - The definition of 'parental responsibility' or 'parental rights' under section 5 of the MHR Act be amended so that:
 - a person has parental responsibility/parental rights if under a parenting order the child is to spend unsupervised time with the person; and
 - a person does not have parental responsibility/parental rights if he/she has a restraining/personal protection order preventing them from spending time with the child under the *Family Law Act 1975* (Cth) (**Family Law Act**) or a law of a State or Territory unless there is a Family Law Act order providing that person has parental responsibility for the child.

- The MHR Act be amended to include the provision in the Framework to guide the secondary use of My Health Record System data (**the Framework**) that secondary use of MHR data is not permitted for solely commercial and non-health-related purposes, and will not be provided to insurance agencies.
 - The default for secondary research use of data should require the informed consent of the healthcare recipient. This consent can be readily sought and obtained through the user settings and communication channels facilitated by the MHR system between individuals and prospective researchers.
 - Increased accessibility functions and options be built in to MHR, including language options, videos, diagrams and images, to make it easier to use for all consumers.
 - The Australian Government invest in initiatives that offer individuals with lower levels of digital and online literacy the opportunity to participate in education and training with a view to enabling them to become competent and confident users of the MHR system.
 - The Inquiry consult further with health practitioners about assisting patients with their MHR in a way that provides health practitioners with reasonable remuneration for their expertise and time to do so.
 - In relation to children and young people doctors ask child patients if they want sensitive information about their visit or prescribed medications blocked via an Access Code, and act accordingly to do so. The LIV notes, however, that this solution is not preferred, as the act of blocking access would alert a parent to the fact that a particular record exists that the child has deliberately chosen not to share with the parent.
 - Consideration of possible safeguards to limit the risk of MHR being used inappropriately within an elder abuse context.
 - Regard is had to principles of Indigenous data sovereignty.
 - A feature is added to the MHR that notifies a patient that a health practitioner wishes to upload an advance care document to their MHR, and requiring the patient to review and approve the document before it can appear on their MHR.
5. The Law Society of New South Wales (**LSNSW**) makes the following separate recommendation:
- That clarification be provided on how NSW health providers can comply with Health Privacy Principle 9 under the *Health Records and Information Privacy Act 2002* (NSW) when considering the relevance, accuracy and completeness of the MHR.

Background

6. The MHR system contains online summaries of an individual's health information. This includes the medicines they have consumed, the allergies they may experience, and the treatments they have received.¹ MHR replaced PCEHR. The PCEHR was not regularly used by healthcare providers, leading to a decline in demand, with registrations just over 1 million users.²
7. The *Review of the Personally Controlled Electronic Health Record (PCEHR Review)* identified the following issues:
 - not enough patients registered to provide clinical value;³
 - not enough information in patient records to provide clinical value;⁴
 - poor integration with healthcare practices;⁵ and
 - the PCEHR interface was not conducive to practical clinical use.⁶
8. However, the PCEHR review found that there was still a place for an e-health system in Australia. It suggested that fixing the flaws of the PCEHR would benefit the healthcare industry.⁷

Recommendation

- **The MHR system should build on the lessons from PCEHR.**

Current arrangements

9. MHR allows an individual's doctor, hospital or other healthcare providers (such as physiotherapists) to view their health information, in accordance with their access controls. Individuals are also able to access their record online. The following table details the legislative framework for the MHR system:

My Health Records Act 2012:

- The Act establishes a System Operator whose functions include maintaining an index service.⁸ The index service connects information in different repositories to 'registered healthcare recipients'.⁹
- A healthcare recipient is an individual who has received, receives or may receive healthcare.¹⁰ The registration of a 'healthcare recipient' is determined by the System Operator.¹¹

¹ Australian Digital Health Agency *What is in a My Health Record?* <<https://www.myhealthrecord.gov.au/for-healthcare-professionals/what-is-in-my-health-record>>

² Report into the Personal Controlled Electronic Health Record (December 2013), 6.

³ Ibid.

⁴ Ibid 39.

⁵ Ibid.

⁶ Ibid.

⁷ Ibid.

⁸ *My Health Records Act 2012* (Cth) s 15(a).

⁹ Ibid s 15(a)(i).

¹⁰ Ibid s 5.

¹¹ Ibid s 41(1).

- The index service also allows for the retrieval of information when required.¹² It ensures that registered healthcare recipients in the MHR system are authorised to collect, use and disclose information.¹³

My Health Records Regulation 2012:

- The Australian Digital Health Agency (**ADHA**) is the System Operator.¹⁴
- The prescribed information to be included in a My Health Record relates to the provision of healthcare to the healthcare recipient.¹⁵

My Health Records Rule 2016:

- The ADHA must establish and maintain default access controls.¹⁶
- These controls permit all registered healthcare provider organisations, involved in the care of a recipient, to access the recipient's MHR.¹⁷ They also permit a recipient to view the access list for their MHR.¹⁸
- Recipients are also able to remove records from their MHR,¹⁹ and authorise the ADHA to restore records which have been removed.²⁰
- The access controls also permit registered healthcare providers that upload records to a recipient's MHR to access the records, but only by request to the ADHA.²¹

¹² Ibid s 15(a)(ii).

¹³ Ibid.

¹⁴ *My Health Records Regulation 2012* s 2.1.1.

¹⁵ Ibid s 4.1.1.

¹⁶ *My Health Records Rule 2016* s 5.

¹⁷ Ibid s 5(a).

¹⁸ Ibid s 5(c).

¹⁹ Ibid s 5(e)(i).

²⁰ Ibid s 5(e)(ii).

²¹ Ibid s 5(f).

Expected benefits

10. In Australia, automated data gathering has proven useful in other areas. For example, the Australian Taxation Office automatically gathers information about a taxpayer's wage and salary, interest payments from financial institutions, share dividends, and property sales, for the purposes of their electronic tax return.²² Benefits that might arise from the digitisation of health records include:
 - providing precise, up-to-date, and comprehensive information about a patient at the time and place of care;
 - helping providers effectively diagnose conditions and reduce errors, thus providing safer care;
 - improving communication between patients and providers;
 - assisting co-ordination of care and the provision of medical history between multiple treating practitioners;
 - addressing fragmentation of care and reducing the risk of negligence resulting from poor communication or failures to follow-up;
 - providing patients with a practical, easily accessible archive of their medical and health history;
 - enabling safer and more reliable prescribing;
 - promoting legible, complete documentation and accurate billing; and
 - decreasing costs through reduced paperwork and duplication of testing.
11. The Law Council has received feedback from the LIV that practitioners involved in compensation claims arising from medical negligence have noted the critical role failures of communication have played in poor medical treatment outcomes. These failures include incomplete medical histories being obtained, for example, from a patient presenting to hospital with complications post operatively, hospitals failing to seek additional information from other treating health providers, such as the patient's general practitioner, and referring doctors failing to pass on critically relevant health information. Other instances involve test results not being forwarded on or not being properly communicated to other health practitioners involved in the patient's care. LIV members have also been involved in cases involving poor processes for documenting allergies, patient sensitivity to medications or dependency on analgesic medication involving 'doctor shopping'. Access to a patient's digitised health records will likely enhance patient safety by enabling health care providers access to critically relevant health information.
12. In addition, the health summary functions of MHR will be helpful for people with any disability that affects their ability to explain their health history to others.²³ As many as one in five Australians have a disability.²⁴ Those with communication difficulties are

²² Australian Taxation Office *How We Use Data Matching* (3 May 2018) < <https://www.ato.gov.au/About-ATO/Access,-accountability-and-reporting/In-detail/How-we-use-data-matching/>>

²³ The Conversation, *Why Aren't More People Using the My Health Record* (24 March 2017) < <https://theconversation.com/why-arent-more-people-using-the-my-health-record-73606>>

²⁴ Australian Bureau of Statistics *Disability, Ageing and Carers, Australia: Summary of Findings, 2015* (18 October 2016) < <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0>>

three times as likely to experience a preventable adverse event while in hospital,²⁵ and generally receive a lower quality of care.²⁶

13. Further, there may be benefits to record keeping. For example, in 2018, hundreds of medical files were found at the former Garrawarra Centre for Aged Care in Helensburgh, New South Wales.²⁷ The files, which had been mixed up with finance documents, were left behind when residents moved to a new facility. They contained personal information, such as specific conditions, treatments and medications, belonging to more than 400 patients from 1992 to 2002.²⁸
14. Similarly, in 2017, John Fawkner Private Hospital was investigated for breaching the privacy of patients after paper records were found in a street.²⁹ The documents referred to depression, weight loss surgery, dementia and incontinence, and included patients' names, ages, diagnoses, treatment plans, medications, and the days they had been in hospital, and whether they lived alone.³⁰
15. The Law Council is also of the view that there is an obvious practical benefit to a single point of data entry for medical records for children and separate parents. Under the MHR system, each parent, who is an authorised person, is able to access the records of their child. For separated parents who take their child to different medical practitioners, each practitioner will have access to the entire health records of the child, so they will be able to best treat the child. However, the Law Council is concerned that in the context of separated families there is a potential risk for misuse of information available from a child's health records. This is discussed further below.

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

16. The Law Council has previously commented on the decision to shift the MHR system from opt-in to opt-out.³¹ The Law Council notes that it is anticipated that as the MHR develops and expands the types of information captured, the database will become an important resource for health, clinical and medical research.³²
17. The Law Council supports the availability of comprehensive databases to aid research, subject to appropriate protection of privacy. One of the reasons why the PCEHR Review recommended an opt-out system for MHR was the low awareness of the PCEHR.³³ By the *My Health Records (National Application) Commencement Instrument 2018*, the MHR opt-out period commenced on 16 July 2018. Every individual with a Medicare or Department of Veterans' Affairs card who does not

²⁵ Gillian Bartlett, Regis Blais, Robyn Tamblyn, Richard J. Clermont, and Brenda MacGibbon, 'Impact of patient communication problems on the risk of preventable adverse events in acute care settings' (2008) *Canadian Medical Association Journal* 178(2), 1555-1562.

²⁶ *Ibid.*

²⁷ Australian Broadcasting Corporation *NSW Government Criticised after Hundreds of Medical Files Found Abandoned in Derelict Aged Care Building* (3 August 2018) < <http://www.abc.net.au/news/2018-08-03/nsw-government-criticised-for-medical-file-privacy-breach/10068038> >

²⁸ *Ibid.*

²⁹ *The Age Dozens of Patients' Medical Records Found Lying in Melbourne Street* (26 March 2017) < <https://www.theage.com.au/national/victoria/dozens-of-patients-medical-records-found-lying-in-melbourne-street-20170324-gv62op.html> >

³⁰ *Ibid.*

³¹ Law Council of Australia, Submission to HealthConsult, *Development of a Framework for the Secondary Use of My Health Record Data Public Consultation Paper*, 17 November 2017, 2.

³² Department of Health and HealthConsult, *Development of a Framework for Secondary Use of My Health Record Data Public Consultation Paper* (1 September 2017) 6 < <https://consultations.health.gov.au/health-systems-policy-division/developing-a-framework-for-the-secondary-use-of-my> >.

³³ Report into the Personal Controlled Electronic Health Record (December 2013), 28.

already have a record will now be automatically registered to have a MHR. There are a range of benefits that come from the implementation of an opt-out system. These include:

- a wider uptake of the system, especially among vulnerable and disadvantaged consumers who do not have the resources to opt-in to the system; and
- healthy consumers, who may not have signed up to the PCEHR, will now have a MHR. This will prove valuable if they experience an unexpected illness or injury that necessitates ongoing treatment.

18. The Law Council notes that the Australian Medical Association (**AMA**) supports the opt-out mechanism for the MHR system.³⁴ The AMA is of the view that the opt-out mechanism ensures high uptake, which maximises utility of the system. The AMA further submitted that the amendments under the My Health Record (Strengthening Privacy) Bill 2018 offer a greater level of protection than other health data systems, in addition to the current protections within the system that allow patient choice, access and control. The AMA however acknowledged that education on the MHR system must be improved, to ensure that consumers, the public and providers have a better understanding and knowledge of the system, in particular regarding the controls that patients are able to apply. This level of education would address the issue of informed consent and the opt-out mechanism, which is explained further below.
19. The PCEHR Report noted that ‘mechanisms will still be in place to support consumer choice, as opting-out will remain an option for those who do not wish to participate’.³⁵ However, this is not the case. Under the MHR Act the Minister may apply the opt-out model to all healthcare recipients in Australia.³⁶ In doing so, the Minister has determined that individuals only have until 15 November 2018 to advise the ADHA, as the System Operator, if they do not want a MHR to be automatically created for them.³⁷ Clearly, this does not mean that opting-out will ‘remain an option’.
20. Opt-out systems for organ donation can be used as a point of comparison. These systems operate in many countries. For example, in Spain, all citizens are automatically registered for organ donation unless they choose to state otherwise.³⁸ The ability to opt-out of the system is always available.³⁹ Similar schemes in Austria, Belgium, France and Sweden also allow citizens to opt-out of organ donation.⁴⁰
21. If an individual misses the opt-out deadline and a MHR record is created for them, the individual can cancel their MHR record at any time. Once cancelled, a health practitioner will not be able to access that record, even in an emergency. However, it is important to note that any data added to a MHR prior to cancellation will be kept for 30 years after death (or 130 years after birth, if date of death is unknown).

³⁴ Evidence to the Community Affairs References Committee, the Australian Senate, Parliament House, 11 September 2018, 31-36 (Dr Kean-Seng Lim, President, Australian Medical Association, New South Wales, Dr Chris Moy, Australian Medical Association Federal Council; Chair, Federal Ethics and Medico-Legal Committee, Australian Medical Association and Mr Luke Toy, Director, Medical Practice Section, Australian Medical Association).

³⁵ *Ibid* 29.

³⁶ *My Health Records Act 2012* (Cth) Schedule 1, Part 1, s 2(1).

³⁷ Australian Digital Health Agency, *Opt-out of My Health Record* < <https://www.myhealthrecord.gov.au/for-you-your-family/opt-out-my-health-record>>

³⁸ Brian H. Willis and Muireann Quigley, ‘Opt-out organ donation: On evidence and public policy’ (2014) *Journal of the Royal Society of Medicine* 107(2), 56-60.

³⁹ *Ibid*.

⁴⁰ *Ibid*.

22. An individual who has opted-out of having a MHR, or who has cancelled their record, can apply at any time to create a MHR. It is submitted that this arrangement satisfies current public concerns over individual freedom of choice (the availability of choices, and the easy reversibility of choices made).
23. Further discussion of the decision to opt-out for the secondary research use of data is discussed below in relation to informed consent.

Privacy and security concerns

24. The Law Council welcomes the amendments proposed by the My Health Records Amendment (Strengthening Privacy) Bill 2018, particularly provisions that a warrant, subpoena or court order will be required before health information can be provided by the ADHA to another agency, thereby addressing a matter of significant public concern that the threshold for releasing private medical information to law enforcement agencies was too low. A more detailed submission on this issue will be provided to the Senate Standing Legislative Committee on Community Affairs.
25. Privacy is regulated under a number of different laws. Government and private sector entities, including providers of healthcare, are required to comply with the Australian Privacy Principles under the Privacy Act. Some entities may also be subject to regulation under separate State and Territory privacy laws. There are additional regulatory protections that apply to the collection, use and disclosure of personal information that is health information, due to its particularly sensitive nature.
26. The utilisation of a single repository of sensitive health information will inevitably entail some risks, and that these risks should be weighed against the benefits of the system to ensure that an appropriate balance is obtained between privacy, security and utility.

Vulnerability of the system to unauthorised access

27. The Law Council notes that one of the more major risks for the MHR system is the possibility of unauthorised access to the system by way of cyber-attack. Digital health records and databases, though they have several advantages over physical record keeping, are not watertight. In March 2018, medical records held by Telstra Health were left exposed to cyber-attacks due to a flaw in its medical software, called 'Argus'.⁴¹ The Argus software is used by hospitals, general practitioners, specialised, primary health networks and allied health care providers and allows healthcare professionals to share patient information. It was identified that the breach could have given an attacker access to download a copy of the medical server's database, although it is not believed that that occurred in this instance. The Law Council submits that the ongoing system design of MHR should be cognisant of similar issues arising from remote desktop connections.
28. A number of issues of public concern in relation to privacy of MHR data have been identified, including:
 - the length of time personal health records are kept (30 years after an individual's death, or 130 years after their birth if the date of death is unknown), even where a user cancels their MHR. On this point, the Law Council queries whether, if a

⁴¹ Ben Grubb, 'medical records exposed by flaw in Telstra Health's Argus software', *The Sydney Morning Herald* (online), 22 March 2018 <https://www.smh.com.au/technology/medical-records-exposed-by-flaw-in-telstra-health-argus-software-20180322-p4z5ko.html>.

MHR has been cancelled, that information can be the subject of subpoena and discovery in court proceedings (where those records are relevant);

- the ability of a health practitioner to access an individual's personal health data that does not relate to medical treatment they are seeking, and may have a discriminatory effect (for example, a person's mental health or psychiatric history being accessible by their dentist, or podiatrist, or discrimination resulting from a record of certain conditions, such as HIV);
- the private healthcare industry is the most prevalent sector for reported data breaches under the Notifiable Data Breach scheme, with 49 notifications (that is, a breach of personal data security that is likely to result in serious harm) between April and June 2018.⁴² However, this does not include public state-based hospitals, which are not covered by the Scheme, and are exempted from the Privacy Act; and
- unauthorised access to a MHR may be inadvertently facilitated by the workplace practices of health care providers.⁴³ These staff practices may include using generic passwords, and allowing multiple staff to access the logged-in computer of one individual. This can make it difficult for a user to identify and track exactly who has accessed their medical information.

29. However, MHR users can protect their privacy through inbuilt functions within the MHR system, including:

- requesting that specific documents not be added to their record, or removed once they are uploaded;
- restricting access to their record by setting a four to eight digit 'record access codes', which can block access to an individual's entire record, or individual documents, unless a user has the code; and
- users can track all instances where their record is accessed (including by third parties) through an access log and receive real time notification alerts.

30. The MHR Act establishes the regulatory system for the collection, use and disclosure of health information from an individual's MHR. The Act provides for criminal and civil penalties, in addition to similar penalties under existing state and Commonwealth regulations, including the Privacy Act. In this intersecting regulatory scheme, healthcare organisations and practitioners will need to be mindful of the requirements of each individual scheme, and the particular way in which the data is being used or dealt with:

- when accessing MHR records, a healthcare provider must comply with both with the Privacy Act and the MHR Act;

⁴² Office of the Australian Data Commissioner, *Notifiable Data Breaches Second Quarterly Report Released* (31 July 2018)

<<https://www.oaic.gov.au/media-and-speeches/news/notifiable-data-breaches-second-quarterly-report-released>>

⁴³ Ariel Bogle and Olivia Willis 'Lax Security Culture in Hospitals Could Affect My Health Record Privacy, Insiders Fear', *Australian Broadcasting Corporation* (22 August 2018)

<<http://www.abc.net.au/news/health/2018-08-21/lax-hospital-security-culture-could-undermine-my-health-record/10128274>>

- when uploading patient information to a MHR, health practitioners must comply with both Commonwealth Acts, as well as any state regulation around the type of data being uploaded, or additional consent requirements;
- any information or files downloaded from a patient's MHR, once downloaded, are no longer regulated by the MHR Act and are instead regulated by relevant federal or state regulations governing person and medical information; and
- information obtained from a MHR can only be disclosed to law enforcement agencies by the ADHA. However, if the same information is obtained from a different source, it is possible for the information to be disclosed to law enforcement agencies by a health practitioner.

31. The Law Council provides the following examples of where the system could be accessed by authorised participants for unauthorised reasons.

An individual within a registered healthcare provider organisation viewing the MHR system

32. The Law Council notes that the access history log only shows the registered healthcare provider organisation that has accessed a record, not the specific individual. An ability to show the access records for an individual registered healthcare provider would resolve this concern.

Appropriate IT security practices for small medical practices

33. The Law Council also expresses concerns in relation to the security of small medical practices and whether they do (or have the capability to) observe appropriate IT security practices. The Law Council acknowledges that the My Health Record Rules (**MHR Rules**) require every registered healthcare provider organisation to have a written IT security policy, however the Law Council queries how this requirement would ever be enforced having regard to the large number of general medical practices in Australia and the commensurate variety of IT systems and structures.

Access by employers to medical records of employees asked to undergo a medical check

34. The Law Council is concerned that employers may access the medical records of employees asked to undergo a medical check, which includes health record data not necessarily related to their employment. This may apply to current or former employees, and could lead to employment discrimination based on the information or based on a failure to provide it as requested. Such information would not necessarily have the protection under the Privacy Act in various stages of the employment relationship. In particular, the Law Council notes that personal information that forms part of an *employee record* as defined under the Privacy Act⁴⁴ which is directly related to a current or former employment relationship, is exempt from the privacy protections available under the Privacy Act.⁴⁵

⁴⁴ *Privacy Act 1988* (Cth) s 6.

⁴⁵ *Ibid* s 7B(3).

Recommendation

- consideration be given to removing or qualifying the exemption under section 7B(3) of the Privacy Act; or
- the MHR Act be amended so that there are additional privacy protections for the health records of employees when accessed by employers.

An individual with parental responsibility for a child or young person who may not be the primary caregiver.

35. Of real concern in the context of separated families is the potential for misuse of information available from a child's health records. This includes concerns in the context of individuals experiencing family violence, and the ability of perpetrators to 'track' victims using information uploaded (both by health practitioners, or individuals) to MHR.
36. In response to recommendations made by the Royal Commission into Family Violence,⁴⁶ the Victorian government created the Family Violence Information Sharing Scheme (**Scheme**).⁴⁷ The Scheme began on 26 February 2018. It authorises a select group of prescribed information sharing entities to share information between themselves for family violence risk assessment and risk management. The LIV queries the interaction of the MHR system within the operation of the Scheme, and recommends that comprehensive stakeholder consultation be undertaken in order to ensure that any risks to personal data or safety are properly mitigated.
37. An authorised representative of a healthcare participant includes a person with parental responsibility. The Law Council understands that either party who is an authorised representative can access, amend or delete the MHR of a child. Section 5 of the MHR Act defines a person to have parental responsibility if he/she is a parent of a child and has not ceased to have parental responsibility because of a court order made under the Family Law Act or the law of a State or Territory. Further, under the current definition of a person with parental responsibility merely having an order that a child spend time with a person, gives that person parental responsibility under the definition. The current definition under section 5 of the MHR Act is as follows:

'parental responsibility': a person has parental responsibility for a healthcare recipient (the child) if, and only if:

(a) the person:

(i) is the child's parent (including a person who is presumed to be the child's parent because of a presumption (other than in section 69Q) in Subdivision D of Division 12 of Part VII of the Family Law Act 1975); and

(ii) has not ceased to have parental responsibility for the child because of an order made under the Family Law Act 1975 or a law of a State or Territory; or

(b) under a parenting order (within the meaning of the Family Law Act 1975):

(i) the child is to live with the person; or

⁴⁶ Victoria, Royal Commission into Family Violence (2016), *Summary and Recommendations*, 13.

⁴⁷ *Family Violence Protection Amendment (Information Sharing) Act 2017* (Vic).

(ii) the child is to spend time with the person; or

(iii) the person is responsible for the child's long-term or day-to-day care, welfare and development; or

(c) the person is entitled to guardianship or custody of, or access to, the child under a law of the Commonwealth, a State or a Territory.

Note: The presumptions in the Family Law Act 1975 include a presumption arising from a court finding that a person is the child's parent, and a presumption arising from a man executing an instrument under law acknowledging that he is the father of the child.

38. The Law Council suggests that the use and definition of the term 'parental responsibility' in the Act is likely to cause considerable confusion for the public, particularly for separated parents. The term 'parental responsibility' is used in most Parenting Plans and parenting Orders made under the Family Law Act. Parental responsibility under the Family Law Act is defined as 'all the duties, powers, responsibilities and authority which, by law, parents have in relation to children'.⁴⁸It encompasses, for instance, the power that parents have to make decisions about medical treatment for children, about school enrolment and about religious affiliation or instruction for children. Parental responsibility orders made under the Family Law Act do not cover arrangements about how much time a child spends in each parent's care or with which parent a child lives. Those arrangements are made pursuant to the 'parenting order' provisions of section 64B.
39. In contrast, the definition of 'parental responsibility' in section 5 of the MHR Act is very broad, and as stated above does not just encompass parental responsibility as contemplated by the Family Law Act but includes also someone who spends time with a child pursuant to a parenting order. Frequently a parent may retain parental responsibility for a child pursuant to the Family Law Act whilst simultaneously being subject to an interim or final parenting order preventing them from contact with the child or alternatively requiring their contact with the child to occur only under supervised conditions due to the parent posing an unacceptable risk of harm to the child.
40. If proceedings have not commenced, then simply being a child's parent would mean a party has parental responsibility according to law, and thus is entitled to access to the MHRs.
41. Even if family law proceedings have commenced, and an order has been made for sole parental responsibility, if the other parent is spending time (even presumably supervised time) then that parent arguably has parental responsibility under paragraph 5(b)(ii).
42. Access to a child's MHR allows an authorised representative to ascertain the residential address of the child (as well as the other person with parental responsibility) in addition to the address of any treating health care practitioners and pharmaceutical providers. This creates serious issues for children and parents who may be at risk of harm if their location was to be disclosed through the MHR system to the perpetrator of violence. As the MHR system is currently opt-out, this issue must be urgently addressed, and education provided to the community for those who may

⁴⁸ *Family Law Act 1975* (Cth) s 61C.

be at risk of family violence or harm. Some current information available to the public on this issue is provided at **Attachment A**.

43. The ADHA has confirmed that they will use Medicare records to determine who has parental responsibility and access to a child's medical records. A parent needs to opt-out to prevent a MHR being created for a child and accessible to the other parent if he/she is registered as such by Medicare.
44. Parents will be able to apply to change who has parental responsibility for the purposes of the MHR, but it is not clear how straight forward this will be, and what evidence needs to be provided in situations of risk, if there is no court order as to parental responsibility, or a Violence Restraining Order. So, for example, it would be entirely possible for a perpetrator to present a birth certificate naming he/she as a parent and not disclose a Violence Restraining Order or that a family law Court had made an order for the other parent to have sole parental responsibility for the child. The perpetrator could then access the child's health record including location details.
45. Further, the Law Council notes that should a family violence intervention order or other court order be required, this may cause delay in removing a perpetrator's access to a victim's MHR. The Law Council notes that a party who has their parental access changed or altered will receive a notification of their removal.
46. The Law Council notes that an individual has the ability to create a MHR using a pseudonym, which is not identifiable, traceable, or linked to an individual's Medicare information.⁴⁹ A pseudonym account can exist in conjunction with an account in the individual's real name, and the individual can choose to merge the two records at any time.⁵⁰
47. It is unclear what may happen if parents do not agree as to whether they opt-out of the system for their child.
48. The My Health Records Amendment (Strengthening Privacy) Bill 2018 was introduced this month to strengthen privacy measures for health records. This Bill, however, does not deal with aspects of parental responsibility and access as detailed above.
49. In the Law Council's view, the legislation needs to address the protection of location and identity of victims of family violence who seek this information not be shared with perpetrators even if the perpetrator falls within the definition of a person with parental responsibility under the MHR Act.
50. Ideally, the MHR Act would not use the term 'parental responsibility' given the difference in definition of that term in the Family Law Act and the MHR Act. A term such as 'parental rights' might be considered, which is broader and is not a term used in the Family Law Act.
51. To protect the location of victims of family violence, the Law Council recommends the definition of parental responsibility (or such other alternative term) under the MHR Act could be amended as follows (proposed amendments are in bold and underlined):

⁴⁹ North Western Melbourne Primary Health Network *My Health record Fact Sheet – Family and Domestic Violence* <<https://nwmphn.org.au/wp-content/uploads/2018/06/hd229-family-and-domestic-violence-fact-sheet.pdf>>

⁵⁰ Ibid.

'parental responsibility': a person has parental responsibility for a healthcare recipient (the child) if, and only if:

(a) the person:

(i) is the child's parent (including a person who is presumed to be the child's parent because of a presumption (other than in section 69Q) in Subdivision D of Division 12 of Part VII of the Family Law Act 1975); and

(ii) has not ceased to have parental responsibility for the child because of an order made under the Family Law Act 1975 or a law of a State or Territory; or

(b) under a parenting order (within the meaning of the Family Law Act 1975):

(i) the child is to live with the person; or

*(ii) the child is to spend **unsupervised** time with the person; or*

(iii) the person is responsible for the child's long-term or day-to-day care, welfare and development; or

(c) the person is entitled to guardianship or custody of, or access to, the child under a law of the Commonwealth, a State or a Territory.

(d) A person does not have parental responsibility if he/she has a restraining/personal protection order preventing them from spending time with the child under the Family Law Act 1975 or a law of a State or Territory unless there is a Family Law Act 1975 order providing that person has parental responsibility for the child.

Note: The presumptions in the Family Law Act 1975 include a presumption arising from a court finding that a person is the child's parent, and a presumption arising from a man executing an instrument under law acknowledging that he is the father of the child.

52. Section 51 of the MHR Act provides that records can be cancelled upon written request and the My Health Records Amendment (Strengthening Privacy) Bill 2018 (if passed) provides cancelled records will be destroyed. Thus, if there are safety concerns one parent can cancel a child's MHR so that the records cannot be inappropriately used, however, it is unclear what evidence needs to be provided to cancel a record of a child and how long it will take for a decision with respect to an application for cancellation will be made.
53. The Courts, lawyers, doctors, refuge workers and others dealing with victims of family violence should be educated to advise victims that this is a possibility that MHRs may be inappropriately used, and they should apply to amend or cancel the records. The potential for misuse of the information on health records also underlines the necessity for communication between agencies dealing with victims of family violence.
54. In summary, a centralised health record for a child has obvious benefits for separated parents who may take the child to different doctors for treatment. The vulnerabilities of the system however are significant in the inadvertent disclosure of information that may be used by perpetrators of family violence to locate ex-partners and children. The balance is a difficult one. The definition of parental responsibility under the MHR Act ought to create an exception if there have been violence restraining orders made. Although this is a relatively blunt instrument it does provide an immediate barrier and

if unfairly so, then a Family Law Court order for parental responsibility would be needed to fall within the definition of parental responsibility under the MHR Act.

Recommendation

- **The use of the term ‘parental responsibility’ in the MHR Act be replaced with an alternative term such as ‘parental rights’.**
- **The definition of ‘parental responsibility’ or ‘parental rights’ under section 5 of the MHR Act be amended so that:**
 - **a person has parental responsibility/parental rights if under a parenting order the child is to spend unsupervised time with the person; and**
 - **a person does not have parental responsibility/parental rights if he/she has a restraining/personal protection order preventing them from spending time with the child under the Family Law Act or a law of a State or Territory unless there is a Family Law Act order providing that person has parental responsibility for the child.**

Arrangements to exclude third-party access

55. The Framework states that the secondary use of MHR data is not permitted for solely commercial and non-health-related purposes, and will not be provided to insurance agencies.⁵¹ The Law Council supports this position and considers that ensuring data collected will not be shared with third parties outside the health sector, whether for commercial purposes or otherwise, is critical to retaining the trust and confidence of the public.
56. Under the *Healthcare Identifiers Act 2010* (Cth), healthcare providers are prohibited from collecting, using or disclosing a healthcare identifier number to a person’s MHR for employment or insurance purposes.⁵² It is a criminal and civil offence for a breach; up to two years in prison and \$25,200 for an individual or \$126,000 for a corporation. However, given that a patient’s MHR appears to be accessible in the Provider Portal through the use of the patient’s healthcare identifier, Medicare or Department of Veteran Affairs number, this may result in the protection sought to be provided by subsection 14(2) of the *Healthcare Identifiers Act 2010* (Cth) not applying. The Law Council submits that it would be preferable for the position to be clarified and put beyond doubt with a specific provision addressing this issue in the MHR Act. The Law Council recommends that the MHR Act be amended to include the provision in the Framework that secondary use of MHR data is not permitted for solely commercial and non-health-related purposes, and will not be provided to insurance agencies.
57. However, the Law Council notes that there has been limited media coverage in relation to the secondary use framework of MHR system data aspect of the MHR system, and it is the Law Council’s view that this issue is not generally well understood by the public. The Law Council considers that further education should be provided to ensure that healthcare recipients are fully informed that their health data may be used for secondary purposes and that it is an opt-out process in circumstances where a healthcare recipient is already registered for an MHR.

⁵¹ Framework to guide the secondary use of My Health Record system data (May 2018), 23.

⁵² *Healthcare Identifiers Act 2010* (Cth) s 14(2).

Recommendation

- **The MHR Act be amended to include the provision in the Framework that secondary use of MHR data is not permitted for solely commercial and non-health-related purposes, and will not be provided to insurance agencies.**

Children and young people

58. In Victoria, there is no legal requirement that a person under the age of 18 attend medical or health appointments with a parent or guardian. Rather, a health practitioner can only provide a person with medical treatment or prescribe medication if they are able to give informed consent (which will involve the health practitioner considering age and maturity, among other things).
59. Under the current arrangements, parents can choose whether to register a child for MHR as part of the Newborn Child Declaration form in the Parent Pack.⁵³ While the Law Council notes that the MHR system recognises that a child can ‘take control’ of their MHR from the age of 14,⁵⁴ the Law Council understands that parents are still able to manage and view their child’s record on their behalf until the child turns 18. Once the child turns 18, parents will automatically no longer have access to the child’s MHR. However, the Law Council submits that there are a number of significant privacy concerns that particularly impact individuals under the age of 18, for example if they are:
- seeking assistance or professional referral for a mental illness;
 - sexually active, or seeking contraceptive options;
 - seeking a termination of pregnancy through emergency contraception, or surgical and medical abortions; or
 - being tested for sexually transmitted diseases. This particularly affects gay, lesbian and bisexual children who are seeking blood tests for HIV, or taking pre- and post-exposure prophylaxis, as it may act as a way of ‘outing’ their sexuality to their parents.
60. The Law Council proposes that doctors ask independent, child patients if they want sensitive information about their visit or prescribed medications blocked via an Access Code, and act accordingly to do so. The Law Council notes, however, that this solution is not preferred, as the act of blocking access would alert a parent to the fact that a particular record exists that the child has deliberately chosen not to share with the parent.

Older people

61. Currently, an older person can nominate a ‘trusted person’ to access their MHR information and help manage it. The Department of Health states that a trusted person

⁵³ Australian Digital Health Agency *Putting You In Control Of Your Child’s Health Records*, <https://www.myhealthrecord.gov.au/sites/g/files/net4206/f/hd106_mhr_newborn_factsheet_a4.pdf?v=1524052601>

⁵⁴ North Western Melbourne Primary Health Network *My Health record Fact Sheet – Family and Domestic Violence* <<https://nwmphn.org.au/wp-content/uploads/2018/06/hd229-family-and-domestic-violence-fact-sheet.pdf>>

can include a carer or family member.⁵⁵ The Law Council notes that in the vast majority of elder abuse cases, the abuse is perpetrated by a family member of the victim.⁵⁶ The Law Council notes the possible risks associated with allowing a family member to have access to an individual's health records, as explained below. These may include, for example, the possibility that an abuser with access to an older person's MHR may retaliate against the victim if they believe the victim is seeking assistance from a health practitioner in relation to abuse perpetrated, or that an abuser may manipulate the information contained in another's MHR to hide records that may suggest a pattern of neglect or abuse of an older person.

First Nations people

62. The United Nations' *Declaration on the Rights of Indigenous Peoples* specifies that Indigenous people have the right to participate in decision-making on matters which would affect their rights, through representatives chosen by themselves in accordance with their own procedures, as well as to maintain and develop their own indigenous decision-making institutions.⁵⁷
63. Unfortunately, there has historically been a lack of First Nations participation in the development of research frameworks and the gathering of data on Indigenous people. This remains a concern in current data collection projects. Thus, 'the collection of data on Indigenous peoples is viewed as primarily servicing government requirements rather than supporting Indigenous peoples' development agendas'.⁵⁸
64. Canada operates a system of multiple electronic health records across each of its provinces and territories. Components include hospital, pharmacy and clinic records, together with laboratory testing, diagnostic imaging, drug information, and public health surveillance.⁵⁹ The system also offers eHealth services to First Nations communities. This reduces travel time and costs, as well as displacement from family and community. It also increases access to opportunities and skills development for providers, empowering patients with choices about their health care, and improving information on health promotion and disease prevention.⁶⁰
65. An evaluation of the system in 2015 noted the need to expand and upgrade the capacity for telehealth initiatives, and ensure operability of all systems across multiple jurisdictions. The evaluation also noted the continued need to work to 'enhance First Nations knowledge, capacity and control over how their data is collected, shared and analysed as well as to increase their involvement in evidence-based decision making with respect to health care service delivery'.⁶¹

⁵⁵ Department of Health *Frequently Asked Questions: Older Australians*

<<https://www.agedcarecomplaints.gov.au/internet/ehealth/publishing.nsf/Content/fags-individuals-older>>

⁵⁶ See, for example, in 71% of calls to the NSW Elder Abuse Hotline in 2015 the perpetrators were family members, with the largest group of perpetrating relatives being adult children: Australian Institute of Family Studies *Elder Abuse: Understanding Issues, frameworks and Responses* (February 2016)

<<https://aifs.gov.au/publications/elder-abuse/3-what-known-about-prevalence-and-dynamics-elder-abuse>>

⁵⁷ United Nations Declaration on the Rights of Indigenous Peoples, GA Res 61/295, UN GAOR, 61st sess, 107th plen mtg, Supp No 49, UN Doc A/RES/61/295 (13 September 2017) art 18.

⁵⁸ Indigenous Data Sovereignty: Toward an Agenda, edited by Tahu Kukutai and John Taylor, ANU Press, 2016

⁵⁹ Canada Health Info way *Electronic Health Records* (2018)

<<https://www.infoway-inforoute.ca/en/solutions/digital-health-foundation/electronic-health-records>>

⁶⁰ Government of Canada *Evaluation of the eHealth Infrastructure Program 2011-2012 to 2015-2016* (2016)

<<https://www.canada.ca/en/health-canada/corporate/transparency/corporate-management-reporting/evaluation/first-nations-inuit-e-health-infostructure-program-2011-2012-2016-2016.html#s5>>

⁶¹ Ibid.

66. The Law Council recognises and supports indigenous control of the methods by which data is collected, how it is used and the purpose of its use. The Law Council submits that principles of Indigenous data sovereignty be kept in mind in the ongoing development and operation of the MHR framework.

Recommendations

- **In relation to children and young people, doctors ask child patients if they want sensitive information about their visit or prescribed medications blocked via an Access Code, and act accordingly to do so. The Law Council notes however that this solution is not preferred, as the act of blocking access would alert a parent to the fact that a particular record exists that the child has deliberately chosen not to share with the parent.**
- **Consideration of possible safeguards to limit the risk of MHR being used inappropriately within an elder abuse context.**
- **Regard is had to principles of Indigenous data sovereignty.**

Informed consent and accessibility

67. The Law Council continues to express concern regarding the potential impact of a default consent for secondary uses upon public trust in the MHR system, as well as the limited clinical utility of data available through the MHR system (given the ability of individuals to control that data).
68. The Law Council does not consider that the policy decision to adopt an opt-out model for creation of My Health Record supports a further decision to adopt an opt-out model for secondary uses of MHR (i.e. health, clinical and medical research). Rather, the Law Council continues to recommend that the default creation of a MHR for an individual should lead to policy caution in adopting a default consent for secondary uses of that individual's MHR.
69. The Law Council recommends that it is preferable that the default for secondary research use of data is to require the informed consent of the healthcare recipient. This consent can be readily sought and obtained through the user settings and communication channels facilitated by the MHR system between individuals and prospective researchers.
70. The Law Council further notes that currently, consent does not need to be obtained from a registered healthcare recipient before a registered healthcare provider organisation uploads a document to the MHR system. The Law Council notes that a registered healthcare provider organisation is authorised to upload clinical information under Schedule 1, Part 2, Division 3, section 9 of the MHR Act.
71. It is the Law Council's view that this fundamental element of the MHR system is at odds with the equitable and ethical duty of confidentiality owed by a health care practitioner to a patient. The Law Council considers that it is also at odds with the underlying principles in both Commonwealth and State privacy laws⁶² which provide that a health entity that holds information about a patient can only use or disclose the information for the particular purpose for which it was collected unless an exception

⁶² *Privacy Act 1988* (Cth) Schedule 1, Australian Privacy Principle 6; *Health Records and Information Privacy Act 2002* (NSW) Schedule 1, Health Privacy Principle 11.

applies. The Law Council considers the primary exception to these principles is that the individual has explicitly consented to a secondary use or disclosure.

72. The Law Council acknowledges that in the MHR system secondary use or disclosure is authorised under the MHR Act. However, the Law Council considers that the intention of the exception in the Privacy Act specifically relates to the need for third parties to obtain information in circumstances where there is an active investigation or court proceedings involving either the healthcare provider or the healthcare recipient. It is the Law Council's view that the exception was not intended to apply to a situation where health information is placed on a national database without the consent of the healthcare recipient.

Recommendation

- **The default for secondary research use of data should require the informed consent of the healthcare recipient. This consent can be readily sought and obtained through the user settings and communication channels facilitated by the MHR system between individuals and prospective researchers.**

Accessibility

73. The Law Council is concerned about the high level of literacy and digital capability necessary to engage with the MHR system, even if only for the purposes of opting out or cancelling their MHR. The Law Council submits that this may be a significant barrier for many users who engage most frequently with the health system, and may benefit the most from MHR.
74. Barriers to effective engagement with MHR will be particularly felt by people with low digital and online literacy, those without reliable access to a computer or the internet, and people from culturally and linguistically diverse backgrounds.
75. Older Australians, people with disabilities, and those who are incapacitated, experiencing declining health or managing chronic health conditions are likely to have the most frequent engagement with the health system, and may benefit most from the ability to record, store and share their personal health and medical information. However, these individuals are also more likely to be prevented from engaging with MHR effectively.

Recommendation

- **Increased accessibility functions and options be built in to MHR, including language options, videos, diagrams and images, to make it easier to use for all consumers.**

Health literacy

76. The difficulties in engaging with an online personal data system may be compounded by Australia's low levels of health literacy: 'the skills, knowledge, motivation and

capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action'.⁶³

77. The National Statement on Health Literacy identified that only 40% of Australian adults possess 'the level of individual health literacy needed to meet the complex demands of everyday life.'⁶⁴ The standard identified that for older people, 'low individual health literacy is associated with a poorer health status and with a higher risk of premature death'.⁶⁵
78. The Law Council acknowledges that remedying access difficulties caused by both digital and health literacy is complex, and requires a multi-faceted approach. The Law Council endorses the systemic and collaborative approaches recommended by the National Statement on Health Literacy.

Recommendation

- **The Australian Government invest in initiatives that offer individuals with lower levels of digital and online literacy the opportunity to participate in education and training with a view to enabling them to become competent and confident users of the MHR system.**

Assisted registration and other health practitioner assistance

79. The Law Council understands that there is currently no Medicare 'code' that allows medical professionals to bulk bill time spent assisting patients with their MHR. The Law Council notes the merits of health practitioners being involved in My Health Record activity with their patients, however, the Law Council is conscious that some health practitioners may feel may see this as a further burden on their limited consulting time.

Recommendation

- **The Inquiry consult further with health practitioners about assisting patients with their MHR in a way that provides health practitioners with reasonable remuneration for their expertise and time to do so.**

Authorised representatives and capacity

80. If an individual wishes for someone else to manage their MHR on their behalf, that person will need to apply to the ADHA by completing an application form and providing supporting documentation.
81. An 'authorised representative' can manage another person's MHR on their behalf. MHR requires proof of an authorised representative's authority to act on another's behalf, such as an enduring power of attorney, enduring guardianship or a guardianship order.

⁶³ Australian Commission on Safety and Quality in Health Care *National Statement on Health Literacy* (2014) <<https://www.safetyandquality.gov.au/wp-content/uploads/2014/08/Health-Literacy-National-Statement.pdf>>,
2.

⁶⁴ Ibid.

⁶⁵ Ibid.

82. To manage the MHR of a person over the age of 18, the authorised representative is required to prove that the individual lacks the capacity to manage their own health record. Demonstrating a lack of capacity requires a written letter to that effect from a medical practitioner or psychologist.⁶⁶
83. While the Law Council supports strong security measures to protect access to personal information, the Law Council notes that authorised representatives may find the authorisation process burdensome. In such circumstances, the Law Council questions the extent to which someone may choose to circumvent these security measures to access and manage the MHR of another by simply requesting that the individual donor supply the person with the donor's personal login data.

Alternative international systems of digitising health records

84. The Law Council recognises the benefits of digital information for high quality healthcare. In some overseas countries, digital records have transformed their paper-based healthcare systems.⁶⁷ For example, Denmark has one of the highest rates of public satisfaction with its health care system.⁶⁸ The implementation of e-health records in Denmark dates to 1996. A series of pilots that sought to develop e-health records identified the need for common standards and terminology.⁶⁹ There have been four e-health strategies since then.⁷⁰ According to a review of the system,⁷¹ each strategy has built on the achievements of its predecessor.⁷² E-health records are now used by nearly all general practitioners in Denmark.⁷³
85. In comparison, the current arrangements of MHR pose legitimate concerns, as described above. These concerns relate to security and confidentiality, the additional workload for professionals, technological literacy issues among disabled and older patients, and the lack of public awareness of MHR. Should these concerns not be resolved, the MHR system may face public backlash, akin to what happened to the United Kingdom's electronic health system.⁷⁴
86. In 2002, the government of the United Kingdom launched the National Health Service Care Records Service. It was intended to deliver an electronic health records system containing patient records from across the United Kingdom. There were problems with poor user requirements analysis, the failure to address patient confidentiality, overambitious timescales, and enormous cost overruns. It was eventually closed down in 2011.⁷⁵

⁶⁶ Australian Digital Health Agency, *Act On Someone's Behalf As An Authorised Representative* (2018) <<https://www.myhealthrecord.gov.au/for-you-your-family/act-someones-behalf-authorised-representative>>

⁶⁷ Patrick Kierkegaard, 'eHealth in Denmark: A Case Study' (2013) 37 *Journal of Medical Systems*.

⁶⁸ Denis Protti and Ib Johansen, 'Widespread Adoption of Information Technology in Primary Care Physician Offices in Denmark: A Case Study' (2010) *Issues in International Health Policy*.

⁶⁹ Dr Rhonda Jolly, 'The eHealth Revolution – Easier Said Than Done', Research Paper No.3 (2011).

⁷⁰ *Ibid.*

⁷¹ *Ibid.*

⁷² *Ibid.*

⁷³ *Ibid.*

⁷⁴ Centre for Public Impact, *The Electronic Health Records System in the UK* <<https://www.centreforpublicimpact.org/case-study/electronic-health-records-system-uk/>>

⁷⁵ *Ibid.*

Other issues

Advanced care planning

87. The LIV notes that in Victoria, the recently commenced *Medical Treatment Planning and Decisions Act 2016 (Vic)* requires a health practitioner to make all reasonable enquiries in the circumstances to determine whether a patient has made an Advance Care Directive, or appointed a Medical Treatment Decision Maker, prior to administering any emergency medical treatment without the patient's consent.
88. The LIV considers that MHR's system capability for a patient to upload their advance care planning documents (whether this be an Advance Care Directive, or an Appointment of a Medical Treatment Decision Maker) in MHR, in addition to making free-text notes on their MHR, is a feature likely to be of benefit to health practitioners in this respect.
89. Despite this, although just over 6 million Australians have now registered for a MHR, only 2707 advance care planning documents have been uploaded to MHR.⁷⁶
90. The LIV understands that a health practitioner is not able to upload advance care planning documents on behalf of a patient, or make notes on the location of a patient's advance care planning documents. The LIV submits that health practitioners should have the same ability to upload advance care documents that they hold on behalf of their patient to that patient's MHR. The LIV recognises the importance of a user retaining control of their advance care planning documents and records, and recommends that this can be addressed by adding a feature that notifies a patient that a health practitioner wishes to upload an advance care document to their MHR, and requiring the patient to review and approve the document before it can appear on their MHR.
91. The LIV notes that there is currently no national register or repository for advance care planning documents to be stored and accessed remotely, and that in this context, MHR has potential to expand its functionality and presence so that more health and legal practitioners are able to encourage their clients to upload their advance care planning documents.

Recommendation

- **A feature is added to the MHR that notifies a patient that a health practitioner wishes to upload an advance care document to their MHR, and requiring the patient to review and approve the document before it can appear on their MHR.**

Accuracy and amendment of the My Health record

92. The LSNSW notes that in NSW, pursuant to the *Health Records and Information Privacy Act 2002 (NSW)*, an organisation is prevented from using health information without taking reasonable steps to ensure the information is relevant, accurate, up to

⁷⁶ Australian Digital Health Agency, *My Health Record Statistics* (August 2018)
<https://www.myhealthrecord.gov.au/sites/g/files/net5181f/my_health_record_dashboard_-_19_august_2018_4.pdf?v=1535000401>

date, complete and not misleading.⁷⁷ It is unclear how health service providers in NSW can comply with this principle.

93. The LSNSW considers that it is also unclear how the ability of individuals to set access controls or withdraw consent for upload of certain health information will impact on the relevance, accuracy and completeness of the MHR. The LSNSW considers that this could result in:
- individuals either inadvertently or intentionally rendering their MHR irrelevant, inaccurate and incomplete; or
 - health care providers being unable to use the MHR.
94. The LSNSW notes that under NSW legislation an organisation that holds health information must also, at the request of the individual, make appropriate amendments to ensure health information is accurate, relevant, up to date, complete and not misleading, with some exceptions.⁷⁸
95. The LSNSW considers that there is currently no clear mechanism or process for:
- an individual to apply for amendment of health information contained within their MHR; and
 - amendment of health information contained within the MHR.
96. It is the LSNSW's view that it is necessary for these processes to be appropriately clarified.

LSNSW recommendation

- **Clarification be provided on how NSW health providers can comply with Health Privacy Principle 9 under the *Health Records and Information Privacy Act 2002 (NSW)* when considering the relevance, accuracy and completeness of the MHR.**

My Health Record system roll-out

97. The Law Council is concerned that the roll-out of the MHR system, and in particular its opt-out nature, has generated a significant amount of inconsistent messaging to the public that has served to potentially undermine the effectiveness and use of the system.
98. In particular, the Law Council considers there is a need to:
- confirm the messaging in respect of the amendments and safeguards made as a result of the issues regarding accessibility of records and access to those records;
 - ensure consistency of communications in light of current public confusion; and
 - ensure greater accessibility and further time for the utilisation of opt-out mechanisms by the general public.
99. The Law Council also holds concerns about the quality of information provided to the public through medical practitioners. The LSNSW has been informed from practitioner

⁷⁷ *Health Records and Information Privacy Act 2002 (NSW)* Schedule 1, Health Privacy Principle 9.

⁷⁸ *Ibid*, Health Privacy Principle 8.

members that financial incentives have been provided by the Government to medical practitioners to assist with administrative costs relating to uploading records into the MHR system. However, the LSNSW notes that there has been limited training provided for medical practitioners in relation to providing patients with the benefits and risks of the MHR system so they have sufficient information to make an appropriate election.

Attachment A

Information available to the public regarding opting out a child from My Health Record

From the Office of the Australian Information Commissioner website:

How do I opt-out a child from having a My Health record created?

“If a child under the age of 18 is listed on your Medicare card and you have parental responsibility for the child, you will be able to opt the child out between 16 July 2018 and 15 November 2018 via the online portal or Help line (1800 723 471). If the child is not on your Medicare card, you will be required to provide other evidence of your parental responsibility, such as a birth certificate, court order or parenting orders in order to opt-out. Where no one has parental responsibility for a child, a person with legal authority can opt-out a dependant under 18. Where there is no one with parental or legal authority for a child, an otherwise ‘appropriate’ person can opt-out a dependant under 18. You will need to support your claim to be an ‘appropriate person’, for example, with a statutory declaration. To find out how to opt-out a child who is not on your Medicare card, visit the My Health Record website or call the My Health Record helpline on 1800 723 471.”

How do I become an authorised representative if a child was not opted-out?

“If a child is not opted-out and therefore has a My Health Record created for them, you can apply to become an authorised representative for that child. As an authorised representative, you will be able to manage the child’s My Health Record on their behalf. This includes determining which healthcare providers may access it and whether any other persons (including the child) may access it. It is important to understand that if the child is listed on your Medicare card and you have parental responsibility for the child, you will not automatically become the child’s authorised representative. To find out how to become an authorised representative for a child, visit the My Health Record website or call the My Health Record Help line on 1800 723 471.”

From the office of the Australian Digital Health Agency

1. When creating a My Health Record the Australian Digital Health Agency uses Medicare records to determine who has parental responsibility.
2. That if neither parent opts out a My Health Record will be established for each child and both parents, if recorded at Medicare will be deemed to have parental responsibility and will have access to it.
3. That the Australian Digital Health Agency will consider applications to remove one parent from having parental responsibility and will want to see copies of Violence Restraining Orders and/or court orders.
4. If an application is made to cancel a record and it is successful the record will be cancelled immediately, but will be kept in archives if required (only very limited people have access to archives but archives will be available if there is a court order).
5. There is some uncertainty if a subpoena has the same effect of an Order under section 69 of the MHR Act but this is likely.

Move by parliament to limit scope of access

My Health Records Amendment (Strengthening Privacy) Bill 2018 introduced to parliament on 22 August 2018 will (if passed):

1. Remove the ability for the System Operator to disclose health information to law enforcement agencies and government agencies without an order by a judicial officer or the healthcare recipient's consent.
 2. Require the System Operator to permanently delete from the National Repositories Service any health information about a healthcare recipient who has cancelled their My Health Record.
- ❖ ***Thus, if either parent cancels their child's health record account the information is to be permanently deleted but will one or other will have to actively cancel the child's record.***