

Should Australians opt out of My Health Record?

What they said...

'The more you dig into the creation and use of these databases and the potential for misuse, the more concerning it becomes'

Kerryn Phelps, former Australia Medical Association president and Independent federal member for Wentworth

'People will have control over their records. They will be able to set who can access them and control who has access to see different parts of their record. They will also be able to see who has accessed their records'

Sue Walker, Queensland University of Technology Health Information Management senior lecturer

The issue at a glance

The My Health Record is an online summary of an individual's health information which began to be established in 2016. It is intended to supply a centralised record of a patient's medical history which can be easily accessed and used by a range of medical practitioners. On November 14, 2018, the federal Health Minister, Greg Hunt, extended the opt-out period for the My Health Record system until January 31, 2019.

Those Medicare card holders who do not make a choice by the new cut-off date, will have a My Health Record automatically created for them.

<https://www.abc.net.au/news/science/2018-11-14/my-health-record-opt-out-deadline-amendments-privacy-security/10481806>

About six million Australians already have records and about 1.15 million have decided to opt out. About 300,000 have opted in and about 17 million are expected to be automatically enrolled once the deadline passes. <https://www.news.com.au/lifestyle/health/my-health-record-should-you-opt-out/news-story/d31d492dffaf3788ba9851e73073f482>

Software analysts, civil libertarians, unions and advocates for victims of family violence have raised privacy and security concerns about the system. On the other hand, some health groups have stressed its benefits in helping clinicians access patient health records and so provide more effective care.

Background

The information below is abbreviated from two sources: the Wikipedia entry titled 'Australian Digital Health Agency'

https://en.wikipedia.org/wiki/Australian_Digital_Health_Agency and the My Health Record Internet site. <https://www.myhealthrecord.gov.au/>

The Australian Government has a policy to development a lifetime electronic health record called My Health Record. This was initially deployed in July 2012, and is under active development and extension by the Australian Digital Health Agency at a cost of \$2 billion. The agency was established in 2016.

Unless they opt out by 15 November 2018 all Australians with a Medicare card will have a My Health Record automatically created in their name. Opting out has to be done by telephone. In October, 2018, 1,147,000 had opted out, but the agency, and the Health Minister Greg Hunt declined to update the figure before the deadline. Those who wish to opt out subsequently can have their record deleted. The records cannot be released to police or

government agencies without a court order. Hunt subsequently extended the deadline to January 31 2019 and increased penalties for those who misuse the system, doubling the level of fines to \$315,000 and increasing the maximum jail sentence to five years.

What is My Health Record?

My Health Record is an online summary of an individual's health information available to all Australians.

Healthcare providers authorised by their healthcare organisation can access My Health Record to view and add to their patients' health information.

My Health Record does not replace existing health records. Rather, it supplements these with a shared source of patient information that can improve care planning and decision making.

Information available through My Health Record can include, information available through My Health Record can include a patient's shared health summary (e.g. diagnoses, current medications, allergies and adverse reactions); medication prescribing and dispensing history; the Medicines Information View; discharge summaries; specialist letters; referrals; information about a patient's past health events and pathology reports.

As more people and healthcare organisations use the My Health Record system, Australia's national health system will become better connected. A My Health Record will be created for every Australian by the end of 2018, unless they choose not to have one.

The medical databank

Two years of data from the Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, Australian Immunisation Register and Australian Organ Donor Register will be automatically updated the first time a patient's doctor looks at his/her record.

Otherwise it's up to the patient's doctor to upload the information and they will decide what records to put on the patient's file.

Accessing a patient's My Health Record

Providers associated with organisations already registered for My Health Record can access a patient's My Health Record in two ways:

Through hospital and practice-based clinical information systems that are My Health Record-ready;

Over the web, through a desktop, tablet or mobile phone web browser.

Any registered health provider like a doctor, pharmacist, physiotherapist, nurse, diagnostic imaging and pathology practice will be able to see a patient's record.

Others registered with the Australian Health Practitioner Regulation Agency, such as a chiropractor, optometrist, osteopath, dentist, psychologist and Chinese medical practitioner will also be able to access a patient's medical data.

Security and privacy

Security is a key design element of the My Health Record system, which adheres to Australian Government security requirements. My Health Record data is stored in Australia, and is protected by high grade security protocols to detect and mitigate against external threats. The system is tested frequently to ensure these mechanisms are robust and working as designed.

Internet information

On December 6, 2018, news.com.au published an analysis titled 'My Health Record: Should you opt out?' which outlines the advantages and disadvantages of being in the My Health Record system.

The full text can be accessed at <https://www.news.com.au/lifestyle/health/my-health-record-should-you-opt-out/news-story/d31d492dffaf3788ba9851e73073f482>

On November 15, 2018, the consumer magazine Choice published a report titled '\Stay in or opt out?' which presented the advantages and the risks associated with the My Health Record. The full text can be accessed at <https://www.choice.com.au/health-and-body/health-practitioners/online-health-advice/articles/my-health-record-and-what-you-need-to-know>

On November 14, 2018, ABC News published a report titled 'The My Health Record opt-out deadline has been extended. Here's what you need to know'

The report detailed the Health Minister's decision to extend the opt-out deadline for My Health Record to January 31, 2019.

The full text can be accessed at <https://www.abc.net.au/news/science/2018-11-14/my-health-record-opt-out-deadline-amendments-privacy-security/10481806>

In November 2018, the Australian Government's Office of the Australian Information Commissioner published 'Privacy resource 23: Handling personal information in the My Health Record system'

The document outlines the procedures to be followed when handling patient information.

The full text can be accessed at <https://www.oaic.gov.au/resources/agencies-and-organisations/business-resources/privacy-business-resource-23-handling-personal-information-in-the-my-health-record-system.pdf>

On October 18, 2018, The Sydney Morning Herald published a report titled 'Major changes to My Health Record laws needed to safeguard Australians, Senate inquiry finds' which details some of the concerns raised in submissions to the Senate Inquiry into My Health Record from privacy advocates, domestic violence campaigners, medical practitioners and unions about the potential for sensitive data to be misused by employers, insurance companies and violent offenders seeking information about the whereabouts of their former partners. <https://www.smh.com.au/politics/federal/major-changes-to-my-health-record-laws-needed-to-safeguard-australians-senate-inquiry-finds-20181017-p50a47.html>

On October 18, 2018, the Senate Inquiry into My Health Record released its recommendations. These can be found on the Australian Privacy Foundation site at <https://privacy.org.au/campaigns/myhr/>

Please note you will need to scroll down the page to locate the recommendations.

On September 20, 2018, Third Horizon published a comment and analysis by the head of the My Health Record program, Andrew Howard, titled 'My Health Record – an essential conversation to have in Australia' which details the advantages potentially available to Australians through the use of My Health Record.

The full text can be accessed at <http://www.thirdhorizon.com.au/my-health-record/>

On August 29, 2018, ZDNet published a comment and analysis titled 'Australian government moves to improve My Health Record privacy' which outlines the provisions of the My Health Records Amendment (Strengthening Privacy) Bill 2018

The full text can be accessed at <https://www.zdnet.com/article/australian-government-moves-to-improve-my-health-record-privacy/>

On August 10, 2018, The Sydney Morning Herald published a report titled 'Unions urge members to opt out of MyHealth Record' which details concerns about employers' and insurers' capacity to access My health Record and the potential threat this represents. The full text can be accessed at <https://www.smh.com.au/business/workplace/unions-urge-members-to-opt-out-of-myhealth-record-20180806-p4zvr6.html>

On August 2, 2018, The Sydney Morning Herald published a report titled 'My Health concessions "woefully inadequate", says former AMA president' which details the concerns of former AMA president and current Independent member for the federal seat of Wentworth, Kerryn Phelps, regarding the operation of My Health Record. The full text can be accessed at <https://www.smh.com.au/politics/federal/my-health-concessions-woefully-inadequate-says-former-ama-president-20180802-p4zv77.html>

On August 1, 2018, ABC News published a report titled 'My Health Record: Greg Hunt bows to pressure, announces changes to address privacy concerns' which details the changes to be made to the My Health Record legislation to ensure police and government agencies cannot access information against a patient's wish without a court order. The full text can be accessed at <https://www.abc.net.au/news/2018-07-31/court-order-needed-for-my-health-record-greg-hunt-says/10058544>

On August 1, 2018, news.com.au published a report titled 'Government succumbs to pressure on My Health Record privacy concerns' which details the changes to be made to the My Health Record legislation to ensure police and government agencies cannot access information against a patient's wish without a court order. The full text can be accessed at <https://www.news.com.au/technology/online/government-succumbs-to-pressure-on-my-health-record-privacy-concerns/news-story/f894608b606e40c291dd1dd5488232a8>

On July 31, 2018, The Sydney Morning Herald published a report titled 'My Health Record a new battleground in family disputes' which details the concerns of advocates against domestic violence that My Health Record could endanger the safety of children and ex-partners fleeing abusive parents. The full text can be accessed at <https://www.smh.com.au/politics/federal/my-health-record-a-new-battleground-in-family-disputes-20180731-p4zunr.html>

On July 25, 2018, The Guardian published an article titled 'Police can access My Health Record without court order, parliamentary library warns' which details the claims made apt the greater police access to medical records which the Parliamentary Library warns is available through My Health Records. The full text can be accessed at <https://www.theguardian.com/australia-news/2018/jul/25/police-can-access-my-health-record-without-court-order-parliamentary-library-warns>

On July 23, 2018, The Sydney Morning Herald published a comment by Dr Tony Bartone, the current president of the Australian Medical Association titled 'My Health Record could save your life one day' in which he details some of the advantages that My Health Record offers Australians. The full text can be accessed at <https://www.smh.com.au/national/my-health-record-could-save-your-life-one-day-20180723-p4zt4z.html>

On July 17, 2018, The Conversation published a comment by Katharine Kemp, Lecturer, Faculty of Law, University of New South Wales, Bruce Baer Arnold, Assistant Professor, School of Law, University of Canberra and David Vaile, Teacher of cyberspace law, University of New South Wales, Faculty of Law. The article is titled 'My Health Record: the case for opting out' and presents three major reasons for opting out of the My Health Record system.

The full text can be accessed at <https://theconversation.com/my-health-record-the-case-for-opting-out-99302>

On June 25, 2018, Medical Republic published a comment by Dr Bernard Robertson-Dunn titled 'The truth about My Health Record' which outlines a number of the deficiencies of the My Health Record system.

The full text can be accessed at <http://medicalrepublic.com.au/truth-health-record/15335>

On May 11, 2018, ITNews carried an analysis by Justin Hendry titled 'Govt releases My Health Record secondary data use plan' which outlines the framework governing secondary use of data from the My Health Record, providing more detail on the approach for releasing 'de-identified' information.

The full text can be accessed at <https://www.itnews.com.au/news/govt-releases-my-health-record-secondary-data-use-plan-490795>

On November 21, 2017, HealthCareIT News carried a report titled 'GPs and hospitals claim My Health Record is not fit for purpose as alarmingly low usage figures are released' noting the low uptake rate among medical practitioners.

The full text can be accessed at <https://www.healthcareit.com.au/article/gps-and-hospitals-claim-my-health-record-not-fit-purpose-alarmingly-low-usage-figures-are>

In November, 2017, the Australian Privacy Foundation posted a document titled 'Value of My Health Record' which suggests that the My Health Record has limited value for patients and clinicians, while offering government a vastly extended opportunity to access citizens' health data.

The full text can be found at <https://privacy.org.au/campaigns/myhr/value-of-myhr/>
More opinions regarding My Health Record can be found on the Foundation's site at <https://privacy.org.au/campaigns/myhr/>

Arguments against remaining in My Health Record

1. My Health Record is not a reliable medical record likely to be widely used by clinicians
One of the major criticisms made regarding My Health Record is that it is not a reliable clinical record.

In an opinion piece published in The Conversation on July 16, 2018, Katharine Kemp, Bruce Arnold and David Vaile, academics who have studied the efficacy of My Health Record, stated, 'Contrary to what many Australians may believe, MHR is not a clinically-reliable medical record, and was not designed to be. It is not up-to-date and comprehensive.'

<https://theconversation.com/my-health-record-the-case-for-opting-out-99302>

The Office of the Australian Information Commissioner has pointed out, 'The My Health Record system contains an online summary of a patient's key health information; not a complete record of their clinical history.' <https://www.oaic.gov.au/resources/agencies-and-organisations/business-resources/privacy-business-resource-23-handling-personal-information-in-the-my-health-record-system.pdf>

Some critics have noted that the My Health Record is not a reliable guide for clinicians regarding a patient's previous medical history. Kemp, Arnold and Vaile note, 'If, for example, a doctor were treating a child in an emergency, the doctor could not rely on an MHR to know what medications the child has been prescribed up to that date.'

<https://theconversation.com/my-health-record-the-case-for-opting-out-99302>

This incompleteness is a result of the manner in which the data is inputted. A lot of the record relies on the patient manually inputting events and treatments. There is a reliance on individuals who are not compelled to update patient records. On June 25, 2018, Medical Republic published a comment by Bernard Robertson-Dunn in which he stated, 'The responsibility for inputting much of the key health data is up to a patient and their GP. My Health Record will not fully populate itself or keep itself up to date. Patients will need to see their GP if there have been any significant changes to their health.'

<http://medicalrepublic.com.au/truth-health-record/15335>

It has been suggested that doctors do not believe they will be able to confidently act on the information supplied by My Health Record. An Australian Medical Association (AMA) survey published on July 13, 2018, found that 52 percent of the doctors surveyed strongly disagreed that My Health Record would improve patient outcomes while a further 24 percent disagreed. Thus 76 percent of those polled did not believe the record would assist significantly in patient care. <https://aushealthit.blogspot.com/2018/07/looks-like-adha-has-lot-of-work-to-do.html>

This lack of clinician confidence in My Health Care may explain its underutilisation. Figures released in September 2017 by the Australian Digital Health Agency, which is rolling out the national repository for health information, show that while 21 per cent of the population has a My Health Record, only 263 specialists were connected to the system, less than 150 hospital discharge summaries are viewed each month by any healthcare organisation, and about 200 GP-generated shared health summaries were accessed by staff working in public and private hospitals in August, 2017. <https://www.healthcareit.com.au/article/gps-and-hospitals-claim-my-health-record-not-fit-purpose-alarmingly-low-usage-figures-are>

Alison Verhoeven, the chief executive officer of the Australian Healthcare and Hospitals Association, has stated, 'I think there are well-founded concerns about the substantial investment that has been made to date in the My Health Record for limited results and the capacity for this to be addressed in a timely and effective manner.'

<https://www.healthcareit.com.au/article/gps-and-hospitals-claim-my-health-record-not-fit-purpose-alarmingly-low-usage-figures-are>

2. My Health Record data is vulnerable to hacking

Critics of the My Health Record claim that any online record is susceptible to hacking no matter how sophisticated the security system. It is claimed that no data storage system can be made fully secure from skilled hackers determined to breach it. Civil liberties advocates are concerned that this susceptibility to hacking endangers people's privacy as it removes protection from their medical histories which can be accessed and misused by hackers.

On July 16, 2018, Nathan Jolly claimed in thebrag.com, in relation to the hacker security of My Health Record, 'Many others have written about the privacy concerns of this scheme..., and with good reason: no digital data which exists in "the cloud" or on any computer connected to a network can ever be truly deemed safe. The Government can assuage your fear with assurances of Fort Knox-type security measures, but Government-ran computer systems are notorious clunky.' <https://thebrag.com/make-no-mistake-your-my-health-record-will-be-hacked-and-made-public/>

On November 15, 2018, Choice published an overview considering the advantages and disadvantages of the My Health Record which noted, 'Centrally stored information always

brings the risk that in the event of a data breach there could be serious implications for you.' <https://www.choice.com.au/health-and-body/health-practitioners/online-health-advice/articles/my-health-record-and-what-you-need-to-know>

As evidence of the capacity of central databases guaranteed by the Australian government to be compromised, Choice reported in July, 2017, that the Medicare details of Australian patients were being sold online by a trader on the dark web.

<https://www.choice.com.au/health-and-body/health-practitioners/online-health-advice/articles/medicare-card-details-sold-on-darkweb-050717>

Critics also warn that though there will be regular security audits of My Health Record, any documents downloaded or created by a doctor could also be stored on their local IT system and the security of this will depend on their system.

<https://www.news.com.au/lifestyle/health/my-health-record-should-you-opt-out/news-story/d31d492dffaf3788ba9851e73073f482>

Critics of the system have noted that similar health record storage systems have been hacked in other countries. In July, 2018, hackers accessed 1.5 million health records in the Singaporean government's online health system. <https://www.abc.net.au/news/2018-08-02/my-health-record-still-not-safe/10063026> In 2016 a Californian hospital paid \$US17,000 in bitcoin as ransom to a hacker who had seized control of its computer systems. A 2017 study of health data security in the United States found that on average, 4.6 million persons are annually affected by theft or loss of protected health information versus 19.4 million affected by hacking and unauthorised use of protected health information.

<http://www.ep.liu.se/ecp/145/009/ecp17145009.pdf>

Dr Nathan Pinski of the Royal Australian College of General Practitioners and an e-health specialist has stated that breaches are as common and as likely in Australia as they are overseas. He stated, 'In Australian cyber security, there are only two types of healthcare organisations — those that know they've been hacked and those that don't know they've been hacked.' <https://www.abc.net.au/news/science/2018-04-18/healthcare-target-for-hackers-experts-warn/9663304>

3. My Health Record data could be used by employers or insurers to the disadvantage of record holders

Opponents of My Health Record are concerned that loopholes in the legislation or a later relaxation of access restrictions could allow employers and insurers to access the private health data of those with a My Health Record

Tom Ballantyne, from Maurice Blackburn Lawyers, has noted that doctors who examine employees would have access to their medical health records unless the worker changed his/her privacy settings. Mr Ballantyne has stated, 'On the face of what's in the My Health Record Act alone, I think it is very clear that a doctor performing an assessment for an employer or insurer could access My Health Record without there being any further consent process.' <https://www.smh.com.au/business/workplace/unions-urge-members-to-opt-out-of-myhealth-record-20180806-p4zvr6.html>

Mr Ballantyne has stated that if the government wanted to ensure that access to My Health Record was not to be used for employment-related health checks and insurance purposes, 'the simplest thing would be to repeat this kind of exclusion clause in the My Health Record Act'. Until this is done, Mr Ballantyne has argued that employers and insurers would be able to use the doctors they employ to access individuals health records.

<https://www.smh.com.au/business/workplace/unions-urge-members-to-opt-out-of-myhealth-record-20180806-p4zvr6.html>

Unions have warned that there is uncertainty over the potential for employers to gain access to the private health data of workers from employer-appointed doctors. Doctors who examine

claimants for insurance companies could also be able to access My Health Records. This has led unions to encourage their members to boycott the new My Health Record system. Unions members to opt out of the system arguing that doctors working for employers, to make pre-employment health checks or for insurance purposes, could get access to and pass on a worker's entire medical history under the new system. The Rail Tram and Bus Union is advising its 35,000 members to opt out of the online health record because many are required to undergo pre-employment safety checks.

<https://www.smh.com.au/business/workplace/unions-urge-members-to-opt-out-of-myhealth-record-20180806-p4zvr6.html>

The Rail Tram and Bus Union National Secretary, Bob Nanva, has stated, 'There is simply no justification for employers to seek access to personal health information that does not directly relate to workplace safety.' <https://www.smh.com.au/business/workplace/unions-urge-members-to-opt-out-of-myhealth-record-20180806-p4zvr6.html>

As an indication of the ease with which insurers might be able to access My Health Record data, The Saturday Paper reported in the week ending August 3, 2018, 'Local appointment booking app service HealthEngine got into hot water just last month when it was revealed to have shared patient information with personal injury lawyers. HealthEngine is one of several apps that have been granted access to the My Health Record platform.'

<https://www.thesaturdaypaper.com.au/news/politics/2018/07/28/the-positives-and-perils-my-health-record/15327000006624>

Privacy and civil liberties advocates are concerned that this personal medical information could be used to discriminate against people when considering them for employment, an insurance policy or an insurance claim. More particularly, workers claiming workers' compensation can also be required to undergo medical examinations. There is concern that their My Health Record data could also be used to impede workers' compensation claims.

<https://www.smh.com.au/business/workplace/unions-urge-members-to-opt-out-of-myhealth-record-20180806-p4zvr6.html>

4. My Health Record could create complications for separated parents, especially parents fleeing abusive ex-partners

Family law experts have warned that the My Health Record system could become a new source of contention between disputing ex-spouses, while risking the safety of women fleeing abusive former partners.

It has emerged that a loophole exists in the system, allowing a parent who does not have primary custody to create a My Health Record on their child's behalf, without the consent or knowledge of their former partner. <https://www.smh.com.au/politics/federal/my-health-record-a-new-battleground-in-family-disputes-20180731-p4zunr.html>

An abusive ex-partner can thereby gain access to details including the location of medical practitioners and pharmacies attended by the child with their primary caregiver, potentially narrowing down the locations of victims in hiding.

Angela Lynch, chief executive of the Women's Legal Service in Queensland, warned that any refusal of access to a child's My Health Record to a parent by the Digital Health Agency could be contested in the Family Court, including by an abusive former partner.

<https://www.smh.com.au/politics/federal/my-health-record-a-new-battleground-in-family-disputes-20180731-p4zunr.html>

Ms Lynch has stated, 'Perpetrators are highly litigious and will use information against victims and family.' <https://www.smh.com.au/politics/federal/my-health-record-a-new-battleground-in-family-disputes-20180731-p4zunr.html>

Ms Lynch has warned that many abusers retained shared parental responsibility of their children, even if apprehended violence orders were in place, because the Family Court was a forum where parties were often forced to compromise.

Unless a primary caregiver has a Family Court order granting them sole parental responsibility in regard to medical treatment, which was rare, a refusal of access to the child's medical data would be unlikely to withstand a legal challenge.

Terese Edwards, chief executive of the National Council of Single Mothers and their Children, said she had 'serious concerns' about the privacy and safety of vulnerable women under the My Health Record system, 'especially if they have had an abusive or controlling person in their life and particularly if there's children involved'.

<https://www.smh.com.au/politics/federal/my-health-record-a-new-battleground-in-family-disputes-20180731-p4zunr.html>

Linda Burney MP, the opposition's spokeswoman on domestic violence, has warned that the government must 'consult with community groups about concerns private information could be accessed by abusive partners in abusive relationships'.

Ms Burnley has stated, 'We strongly urge the government to consult and work closely with advocacy and support groups in the preventing family violence space, to ensure that My Health Record can be used safely by all.' <https://www.smh.com.au/politics/federal/my-health-record-a-new-battleground-in-family-disputes-20180731-p4zunr.html>

The Law Council of Australia's President, Morry Bailes, the Chair of the Privacy Law Committee, Business Law Section, Olga Ganopolsky, and the Chair of the Family Law Section, Wendy Kayler-Thomson and Director of Policy, Dr Natasha Molt appeared before the Senate inquiry into the My Health Records system to request amendments to the definition of parental responsibility under the My Health Record Act. They claimed that these amendments were needed to ensure a child's My Health Record could not be accessed by a parent subject to a domestic violence, restraining order, personal protection order to stop the My Health Record of children being used to track-down victims of family violence.

<https://www.lawcouncil.asn.au/media/news/my-health-record-amendments-must-protect-children-from-dv>

5. A similar system has failed in the United Kingdom

Opponents of the My Health Record claim that it is virtually identical to the British system care.data which ran between 2014 and 2016 before being cancelled due to the failure of its security provisions.

The man in charge of implementing My Health Record in Australia, Tim Kelsey, was also in charge of setting up care.data. Phil Booth, the coordinator of British privacy group Medconfidential, has claimed the similarities between the two systems were 'extraordinary' and he expected the same privacy breaches would reoccur.

<https://www.theguardian.com/australia-news/2018/jul/22/my-health-record-identical-to-failed-uk-scheme-privacy-expert-says>

Mr Booth stated, 'The parallels are incredible. It looks like it is repeating itself, almost like a rewind or a replay. The context has changed but what is plainly obvious to us from the other side of the planet, is that this system seems to be the 2018 replica of the 2014 care.data.'

The similar care.data system in the United Kingdom was cancelled in 2016 after an investigation found that drug and insurance companies were able to buy information on patients' mental health conditions, diseases and smoking habits.

<https://www.theguardian.com/australia-news/2018/jul/22/my-health-record-identical-to-failed-uk-scheme-privacy-expert-says>

Mr Booth has claimed, 'We had the same promise, exactly the same promise. Not used for solely commercial purposes. It's bullshit.'

If you have a commercial company that also works for Australian healthcare services, they then avoid the purely linguistic safeguard of "solely commercial". That has been used by information intermediaries over here, and they then service pharmaceutical companies. It's just smoke and mirrors.' <https://www.theguardian.com/australia-news/2018/jul/22/my-health-record-identical-to-failed-uk-scheme-privacy-expert-says>

In June, 2015, it was revealed that nearly one million people in Britain, who had opted out of the care.data database, were still having their confidential medical data shared with third parties because the Health and Social Care Information Centre had not processed their requests. <https://www.telegraph.co.uk/science/2016/07/07/how-the-nhs-got-it-so-wrong-with-caredata/>

In June, 2016, the United Kingdom's Life Sciences Minister announced the scheme had been scrapped some two years after its roll-out and after a government expenditure of £7.5 million. <https://www.telegraph.co.uk/science/2016/07/06/controversial-50-million-nhs-database-scrapped-quietly-on-same-d/>

Professor Sheila Bird, of Strathclyde University's Department of Mathematics and Statistics, stated with regard to the failure of care.data, 'Data-sharing as proposed by care.data was disastrously incompetent – both ethically and technically. Professionals rebelled and prevailed in outcasting care.data, thereby ensuring that future proposals will not succeed unless both technically proficient and in the public interest.'

<https://www.wired.co.uk/article/care-data-nhs-england-closed>

Critics of the My Health Record have suggested its potential to be afflicted by exactly the same ethical concerns and technical issues as care.data. The former head of the Turnbull Government's Digital Transformation Office, Paul Shetler, has claimed that the My Health Record system shares faults with the withdrawn British system.

Mr Shelter has stated, '“The (Australian) rollout of this has been significantly flawed, it's got a lot of similarities to what happened in the United Kingdom...

(Digital Health Agency) have seen what has worked and what hasn't worked in other countries and they didn't learn from the history.'

<https://www.news.com.au/technology/online/security/australian-governments-controversial-my-health-record-system-slammed-as-failure/news-story/9f45df2927fe0b85c28a461343dd4704>

Arguments in favour of remaining in My Health Record

1. My Health Record should promote better patient care

The central premise of the My Health Record is that each Australia will have an electronic record of their medical history which can be easily accessed by practitioners in order to enhance the quality of care given.

Among the specific benefits claims are that there will be reduced medication errors. When the healthcare provider uses digital health to create or dispense a prescription and uploads the patient's health summary information, other health professionals will be able to make better decisions. For example, if a patient has seen more than two clinicians who have prescribed medications, these clinicians should be able to check current medications and so avoid prescribing contraindicated substances. As a backup, pharmacists will also be able to see the range of medications that have been prescribed, and be able to detect potential issues with a prescription. <http://www.thirdhorizon.com.au/my-health-record/>

An additional advantage claimed for My Health Record is that emergency treatment and treatment for people on holiday will be facilitated. Many patients require treatment from an Emergency Department or at a clinician while on holiday and do not remember their medical history and medications. If their home GP follows the RACGP guidelines, critical

information about the patient's medical alerts, allergies, history and medications will be available. <http://www.thirdhorizon.com.au/my-health-record/>

The importance of an advance like My Health Record when giving emergency treatment has been stressed by the current head of the Australian Medical Association, Dr Tony Bartone, who has stated, 'This is a new attempt, or a new system, to try and bring together a lot of information that currently exists in many different parts of the health system into an online, one-repository forum to assist doctors, especially doctors who don't have a relationship with the patient in front of them in an emergency situation or in an unforeseen circumstance, to do the best they can, and with all of the available information that's around in the system about that patient.' <https://ama.com.au/media/dr-bartone-sky-news-my-health-record>

In addition it has been noted that the process of undergoing pathology testing and gaining access to pathology reports will be streamlined and unnecessary duplication will be avoided. Clinicians are frequently unaware of what tests have been ordered by another clinician. For example, a GP referral may miss key pathology, and so a specialist may order the same tests again. The My Health Record will provide quick and simple access to these results. For a patient – the pathology results will be available online after seven days (or sooner if the GP reviews the results and authorises personal access). <http://www.thirdhorizon.com.au/my-health-record/>

This point has also been stressed by the president of the Australian Medical Association, Dr Tony Bartone, who has stated, 'As well as their GP, patients might be treated in hospital, see specialists and allied health professionals, be referred by different doctors to different pathology labs and diagnostic imaging providers. These realities mean that each doctor who treats the patient doesn't currently have a clear overview of the range of treatments the patient has received.' <https://www.smh.com.au/national/my-health-record-could-save-your-life-one-day-20180723-p4zt4z.html>

It has also been noted that a longitudinal health history may facilitate treatment overtime. There are cases where an event early in life may become relevant in later life – such as taking a drug that might have an unforeseen impact on a patient's health in later years. When new discoveries are made, the patient or their health professional will be able to check back through the history to see if there was an unintended medical risk.

<http://www.thirdhorizon.com.au/my-health-record/>

It has also been noted that My Health Record should make it easier to support dependents with complex or changing medical needs. People who care for family members with complex health issues can have oversight of what decisions, tests or results are uploaded. For example, an aging parent may undergo a test but not know or understand what it's for. With access to health records, the family member may be able to alleviate confusion or seek further advice from the clinician. <http://www.thirdhorizon.com.au/my-health-record/>

It has further been noted that My Health Record will make access to children's immunisation records far easier. Child immunisation records are required for childcare and school. Being able to keep up-to-date and provide evidence quickly and easily is essential for parents and carers. <http://www.thirdhorizon.com.au/my-health-record/>

2. My Health Record data could be used for valuable research

Some proponents of My Health Record argue that access to the data will enable medical researchers to improve the health care provided to all Australians by, for example, detecting disease clusters and observing the mass efficacy of particular treatments.

The potential value of My Health Record data for medical research is explained on the My Health Record information site. The site states, 'By the end of 2018, most Australians will have a My Health Record, and most GPs, pharmacies, hospitals, diagnostic imaging services and pathology labs will be connected to the system. This means there will be an increasing

amount of information available to guide health service planning, policy development and research to further improve Australia's health system.

My Health Record data may be used to provide insight into the effectiveness of the services and treatments being provided to improve health outcomes for patients. 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.'

<https://www.myhealthrecord.gov.au/for-you-your-family/howtos/secondary-uses-data>

In an overview of My Health Record published by Croakey on May 11, 2018, it was suggested, 'The availability of population-wide and de-identified health data enabled by My Health Record offers huge potential, if privacy and security requirements can be met, in ascertaining what works and what doesn't work in the health system, ranging from medication results to health provider performance.' <https://croakey.org/an-important-overview-of-the-pros-cons-and-questions-about-my-health-record/>

On August 18, 2018, The Sydney Morning Herald published a comment by Crispin Hull, who was appointed to the Australian Bureau of Statistics governance advisory panel for measuring Australia's progress in 2011. Hull argues that the My Health Record data should be made available for research purposes. He has stated, 'This data is part of the common wealth and should be available, with identifying material deleted, to all who want to work with it... MyHealth and the computing power behind it should be seen as a great opportunity to build a great medical-research database. It would be impossible to predict the full benefits.' <https://www.smh.com.au/politics/federal/my-health-record-opt-in-and-opt-out-arguments-miss-the-point-20180816-p4zxyt.html>

Hull argues that 'stripped of individual identification the raw data of every interaction between people and the health system would reveal correlations, possible causations, trends, and lines of further inquiry that could lead to better treatments and avoidance of bad ones... With modern computing power the data could reveal astonishingly useful stuff – things like cancer clusters, the effectiveness of drugs, and geographic prevalence of disease. Even drug incompatibilities or bad side effects could be detected well before case-by-case events bleep on the radar... <https://www.smh.com.au/politics/federal/my-health-record-opt-in-and-opt-out-arguments-miss-the-point-20180816-p4zxyt.html>

In December, 2016, the McKell Institute, an independent, not-for-profit, public policy institute, produced a review arguing for greater use within Australia of what it termed 'big data'. The review states, 'Working together, we will be able to use big data to advance medical and pharmaceutical innovation; we will be able to reduce wastage and improve efficiencies in healthcare delivery; and we will be able to prioritise preventative health interventions which will lead to healthier, longer lives for all Australians.'

<https://www.allens.com.au/pubs/pdf/healthcare/Healthcare-McKellReport.pdf>

3. There are provisions in place to protect patient privacy

The My Health Record system is managed in line with the Australian Government Protective Security Policy Framework. My Health Record data is stored in Australia, and is protected by high grade security protocols to detect and mitigate against external threats. The system is tested frequently to ensure these mechanisms are robust and working as designed.

<https://www.myhealthrecord.gov.au/for-healthcare-professionals/howtos/my-health-record-system-security>

Many safeguards are in place to protect the information held in the My Health Record system, such as strong encryption, firewalls, secure login processes and audit logging.

<https://www.myhealthrecord.gov.au/for-you-your-family/howtos/learn-about-my-health-record-system-security>.

The My Health Record system is monitored by the Cyber Security Centre within the Australian Digital Health Agency. All personnel involved with the administration of the system undergo security checks. Australian Digital Health Agency
A range of security processes limit access to the My Health Record system. External software goes through a conformance process before it is allowed to connect to the system. This includes healthcare provider software and mobile applications.

Australian Digital Health Agency uses a range of technology to protect the sensitive personal and health information held in the My Health Record system, including: firewalls to block unauthorised access; audit logs to track access to records; initial and regular anti-virus scanning of documents uploaded to records, and system monitoring to detect suspicious activity. <https://www.myhealthrecord.gov.au/for-you-your-family/howtos/learn-about-my-health-record-system-security>

The privacy of information in the My Health Record system is protected by legislation which includes: My Health Records Act 2012; Privacy Act 1988; Healthcare Identifiers Act 2010 and My Health Records Rule 2016. <https://www.myhealthrecord.gov.au/for-you-your-family/howtos/learn-about-my-health-record-system-security>

The unauthorised collection, use or disclosure of information in the My Health Record system, of healthcare identifiers or of other information collected in relation to either the My Health Record system or Healthcare Identifiers Service is subject to civil and criminal penalties. <https://www.myhealthrecord.gov.au/about/legislation-and-governance>

The Australian Government strongly encourages individuals, business and organisations to take steps to ensure they provide safe and secure digital health services. The Stay Smart Online website offers a lot of useful advice and tips about online security. <https://www.myhealthrecord.gov.au/for-healthcare-professionals/howtos/my-health-record-system-security>

Healthcare consumers link their My Health Record to their myGov account. Accessing their record requires a password, and either an answer to a secret question or an access code. There are additional access controls that the consumer may set to limit access to the entire record, or specific documents within their record. <https://www.myhealthrecord.gov.au/for-healthcare-professionals/howtos/my-health-record-system-security>

4. The government has regularly amended the My Health Record legislation to address stakeholder concerns

The Australian Parliament has made a number of amendments to the original legislation governing the operation of the My Health Card in order to address stakeholder concerns. These amendments are outlined below as presented on the My Health Record site..

'The Australian Digital Health Agency will not approve the release of an individual's personal or health information to a third party except where it is related to the provision of healthcare or is otherwise authorised or required by law. The new measures ensure that insurers and employers are prohibited from using information within your My Health Record, or asking you to disclose your information, for insurance or employment purposes. The primary purpose of My Health Record is to improve your care, and the use of your information for insurance and employment purposes is not healthcare.'

<https://www.myhealthrecord.gov.au/news-and-media/my-health-record-stories/legislation-strengthens-privacy>

'Under the Agency's official operating policy, no information within My Health Record can be released without an order from a judicial officer. To date, the Agency has never received such a request and has never released information. Under these measures, the Agency's policy will be protected in law and will give Australians the assurance that no information can ever be released without oversight from a judicial officer.'

<https://www.myhealthrecord.gov.au/news-and-media/my-health-record-stories/legislation-strengthens-privacy> The purpose of this provision is to regulate the terms under which police or government agencies can access My Health Record data.

'You will be able to permanently delete a My Health Record at any time, if you decide you would no longer like one. No archived copy or back up will be kept and deleted information won't be able to be recovered. A My Health Record that was cancelled in the past (and archived) will also be permanently deleted. If you cancel a record at any time it will be permanently deleted.'

<https://www.myhealthrecord.gov.au/news-and-media/my-health-record-stories/legislation-strengthens-privacy>

Greater privacy is now provided for teenagers aged 14- and over. Under these new measures, once a teenager turns 14, parents will automatically be removed as authorised representatives.

<https://www.myhealthrecord.gov.au/news-and-media/my-health-record-stories/legislation-strengthens-privacy>

Harsher fines and penalties will apply for inappropriate or unauthorised use of information in a My Health Record. Civil fines will increase to a maximum of \$315,000, with criminal penalties including up to 5 years' jail time.

<https://www.myhealthrecord.gov.au/news-and-media/my-health-record-stories/legislation-strengthens-privacy>

There are currently safeguards in place to protect victims of domestic and family violence. Under the changes, the Agency will no longer be obliged to notify people of certain decisions if doing so would put another person at risk. In addition, parents subject to a court order, where they do not have unsupervised access to their child, or who pose a risk to the life, health and safety of the child or another person will no longer be eligible to be an Authorised Representative.

<https://www.myhealthrecord.gov.au/news-and-media/my-health-record-stories/legislation-strengthens-privacy>

5. My Health Record will be empowering for patients

Some supporters of My Health Record argue that the system will be empowering for patients, giving them greater access to and control over their medical records.

On July 16, 2018, The Conversation published a comment by Jim Gillespie, Deputy Director, Menzies Centre for Health Policy & Associate Professor in Health Policy, University of Sydney. Professor Gillespie stated, 'Our health system suffers from a deficit of transparency. Patients are locked out of knowledge of how the system works – from the confusion around private health insurance plans to undisclosed out-of-pocket costs for medical procedures... My Health Record is a small step towards empowering patients with greater knowledge about their health. Pressures to present records in terms that are comprehensible to consumers may even take us towards interactive “learning communities” – the basis of a more people-centred health system. Better-informed patients can enable more effective communication and mutual learning from health professionals.'

<https://theconversation.com/my-health-record-the-case-for-opting-in-99850>

Queensland University of Technology Health Information Management senior lecturer, Sue Walker, has similarly stated, 'E-health initiatives like this have the potential to improve health outcomes for all people by promoting consumer empowerment in their personal health management and helping to deliver effective healthcare.

Having all your medical information in one place, including summary health information from hospitals, specialists and general practitioners, as well as pathology and diagnostic imaging reports, and prescriptions and vaccinations could be empowering for people.'

<https://www.qut.edu.au/news?id=133189>

Ms Walker has further stated, 'People will have control over their records. They will be able to set who can access them and control who has access to see different parts of their record.

They will also be able to see who has accessed their records.'

<https://www.qut.edu.au/news?id=133189>

Relatedly, it has been claimed, that the system is designed not only to give patients the power to access their own records easily, but also to control and be informed of who else has accessed their data.

The Australian Digital Health Agency has stated, 'The My Health Record has been designed to give consumers more control of their healthcare information than ever before in Australia. As a consumer, you can go online and see a summary of who has accessed your information and set up automatic notifications to be sent via email or SMS each time a new healthcare provider accesses your record. This is what a user-centric security model is all about, empowering those who own the information to play a part in protecting what belongs to them. The Cyber Security Centre recommends setting an access code that is given only to healthcare providers you want to access your record and setting up automatic notifications via SMS or email to let the consumer know when their record has been accessed.'

<https://www.digitalhealth.gov.au/about-the-agency/digital-health-space/empowering-healthcare-consumers-to-manage-their-information>

Further implications

The long-term fate of the My Health Record system remains unclear. Though amended enabling legislation has passed the Senate, the system's introduction has been sufficiently vexed to suggest there will be little public tolerance of any misuse of the data.

British experience with a similar system, care.data, suggests that public confidence is vital if the system is to survive. The independent reviewer of Britain's care.data program, Dame Fiona Caldicott, observed, 'Building public trust for the use of health and care data means giving people confidence that their private information is kept secure and used in their interests.' <https://www.thesaturdaypaper.com.au/news/politics/2018/07/28/the-positives-and-perils-my-health-record/15327000006624> The care.data system's well-publicised blunders forfeited that public trust. After the Caldicott report was published, care.data was abandoned. No government is likely to take the political risk of continuing a system such as My Health Record once the electorate has lost faith in either its efficacy or the security of their data.

My Health Record has got off to a shaky start. The federal Health Minister, Greg Hunt, has repeatedly defended it against accusations that there needs to be legislative change to make the system more secure, only to then have to backtrack and, as in the case of police access to the data, amend the laws governing My Health Record.

<https://www.cio.com.au/article/644623/government-amend-my-health-record-legislation/>

It would appear that the initial legislation creating the My Health Record was not well enough considered. Critics of the current system, including many medical practitioners who support it in principle, cannot endorse it in practice because of what they perceive as its present weaknesses. This is the position of Kerryn Phelps, former president of the Australian Medical Association and currently Independent member for the federal seat of Wentworth. <https://www.smh.com.au/politics/federal/my-health-concessions-woefully-inadequate-says-former-ama-president-20180802-p4zv77.html>

There has a raft of demands for legislative reform. The recent Senate Inquiry into My Health Record resulted in dissenting findings from both the Labor and Greens committee members. Labor called for further amendments explicitly to rule out access to My Health Record data for private health insurers, even if data is de-identified, plus a covenant to prevent privatisation of My Health Record records-keeping or outsourcing their maintenance. The party also signalled its intention to seek further privacy enhancements.

<https://www.itnews.com.au/news/senate-inquiry-signs-off-my-health-records-new-private-parts-513877>

The uncertainty surrounding the new scheme has led to repeated extensions of the closing date for the opt-out period for My Health Record. The federal government has now extended the opt out period to January 31, 2019. On October 24, 2018, it was revealed that more than 1.1 million people had now opted out, up from 900,000 on September 12.

<https://www.smh.com.au/politics/federal/morrison-government-under-pressure-to-rewrite-my-health-record-legislation-20181024-p50bom.html> Labor has sought a twelve month extension of the opt out period.

<https://www.theguardian.com/australia-news/2018/nov/14/labor-makes-last-ditch-bid-to-extend-my-health-record-opt-out-period>

In a statement made on November 14, 2018, Labor's health spokeswoman, Catherine King, claimed the Coalition had 'seriously undermined public trust' in the My Health Record system with a 'botched rollout'.

King argued that a 12-month extension of the opt-out period would allow a further public information campaign so Australians can 'make a fully informed choice' about whether to opt out. <https://www.theguardian.com/australia-news/2018/nov/14/labor-makes-last-ditch-bid-to-extend-my-health-record-opt-out-period>

King further called on the government to ask the privacy commissioner to review the My Health Record system and promised Labor, if elected, would do so. That review would consider the balance of utility for clinicians, patients and carers with the privacy of individuals with health records, and protections for vulnerable people including minors and families fleeing domestic violence. <https://www.theguardian.com/australia-news/2018/nov/14/labor-makes-last-ditch-bid-to-extend-my-health-record-opt-out-period>

Despite the ongoing contention, on 26 November 2018, the Australian Parliament passed the My Health Records Amendment (Strengthening Privacy) Bill 2018.

These measures allow Australians to opt in or opt out of having a My Health Record at any time during their life. Records will be created for every Australian who wants one after January 31, 2019. After this date, a person can delete their record permanently at any time.

Under the amended legislation, Australian Digital Health Agency will not approve the release of an individual's personal or health information to a third party except where it is related to the provision of healthcare or is otherwise authorised or required by law. This amendment is intended to prevent insurers or employers accessing the data. Harsher fines and penalties will apply for inappropriate or unauthorised use of information in a My Health Record. Civil fines will increase to a maximum of \$315,000, with criminal penalties including up to five years' jail time. <https://www.myhealthrecord.gov.au/news-and-media/my-health-record-stories/legislation-strengthens-privacy>

The government has pledged 'We will continue to work and consult with relevant stakeholders to continually reduce misuse of the My Health Record system.'

<https://www.myhealthrecord.gov.au/news-and-media/my-health-record-stories/legislation-strengthens-privacy> It remains to be seen how much tolerance there will be within the community if, once the system is in place, there are significant or repeated instances of misuse.