



14 September 2018

**Australian Digital Health Agency submission to the Senate Community Affairs References Committee  
Inquiry into the My Health Record system**

The Australian Digital Health Agency (the Agency) welcomes the opportunity to provide information to the Senate Community Affairs Committee inquiry into the My Health Record system.

Key points we make are:

- The program to create a My Health Record for all Australians by the end of 2018, unless they tell us they do not want one, is the culmination of ten years of planning, design and development carried out under several Health Ministers, current and former federal governments;
- The benefits of a national digital health record have been discussed at length and are supported by key healthcare provider, consumer and industry representative bodies;
- The legislation and program have been scrutinised by several independent enquiries, and shaped by national and international experience on the most appropriate national system for Australia with regard to our federated health system, mix of public and private healthcare, and sentiment of the Australian community;
- The system itself has been in operation for six years and is in a mature state of operation with over 6 million records under management, with all security, privacy, clinical safety and consumer services in operation;
- The transition to opt-out was trialled in two areas in 2016 that involved over 1 million consumers, and experience from those trials has shaped every element of the national expansion; and
- Raising awareness amongst consumers about the My Health Record is an important first step in developing deeper 'digital health literacy' across the population. The transition to opt-out will not be the end of the journey, but the beginning of a new phase of consumer engagement that will empower consumers to play a stronger role in managing their own health information and making better health decisions – supporting Australians to live happier, healthier lives.

## **Background**

The concept of a national digital health record accessible to consumers was formally agreed by Australian governments in the 2008 [National eHealth Strategy](#), which called for an Integrated eHealth Record “to provide a consolidated record of an individual’s health information for consumers to access and as a mechanism for improving care co-ordination between care provider teams”<sup>1</sup>.

This priority considered international experience of the benefits from a whole of health system record where relevant health information followed the consumer. For example, Kaiser Permanente in the US believe that their \$US4B investments in digital health have improved health outcomes of those in their care; reducing death rates due to sepsis by 66%, death rates from stroke by 40% and heart attack by 50%<sup>2</sup>.

It was also informed by experience of an electronic health record in the Northern Territory that was implemented in 2004 – *My eHealth Record* – which was designed to overcome fragmentation of clinical information. Although it was early days in implementation, this system was recognised as a frontrunner for a future national system to support healthcare providers to make informed clinical decisions and improve patient outcomes, which the system ultimately achieved when assessed in an [evaluation study](#).<sup>3</sup>

*The evaluation showed that eHealth records reduced the time clinicians took to find information, and supported improved clinical decision-making and continuity of care for patients.*

Professor Len Notaras, CEO NT Dept of Health, 2015

My eHealth Record was also recognised globally as a World Health Organisation case study in its report [Global diffusion of eHealth: Making universal health coverage achievable](#)<sup>4</sup> which described the record as an “invaluable resource” and emphasised the benefits to the health care needs of the indigenous population.

There were three critical success factors for the system; high levels of consumer participation, active use by healthcare providers across all parts of the health sector, and sufficient clinical content to make accessing the system worthwhile.

Across the rest of Australia, significant work was undertaken by governments and industry to establish a digital health infrastructure that would underpin a connected digital health system and national record, such as implementing unique healthcare identifiers for consumers, healthcare providers and organisations, national authentication measures, a common terminology, and standards for secure electronic messages between healthcare providers.

In 2005, the Productivity Commission released a report into [Australia’s Health Workforce](#) that identified the impact a shared electronic health record could have on productivity in the health sector.

*Greater use of interlinked clinical data through the use of electronic health records, allowing improved access to patient information, would support a more seamless provision of care — such as from primary care to emergency acute care. Such records could also facilitate better coordination and cooperation in a range of other health workforce contexts, offering potential cost savings and benefits to consumers, health service providers and the health system in general.*

Productivity Commission, 2005.<sup>5</sup>

### **Personally Controlled Electronic Health Record**

In 2009, the Australian Government commissioned three separate reviews of options to improve the quality, safety and sustainability of healthcare in Australia. Each report independently identified that investment in a national individual electronic health record system was integral to the realisation of broader health reform objectives for increased access, quality, safety, continuity, and efficiency in care.

The [Primary Health Care Strategy](#) identified information and technology (including E-Health and a national electronic health records system) as one of five building blocks for reform.<sup>6</sup>

The [National Preventative Health Strategy](#) supported the introduction of electronic patient records as a critical success factor for integrated primary healthcare orientated towards preventive health and an important underpinning of the data availability required for individual and population longitudinal prevention strategies.<sup>7</sup>

A key recommendation in The National Health and Hospitals Reform Commission report [A healthier future for all Australians](#)<sup>8</sup> was to introduce a person-controlled electronic health record for each Australian; as one of the most important systemic opportunities to improve the quality and safety of health care, reduce waste and inefficiency, and improve continuity and health outcomes for patients.

*People told us they couldn't believe, with all the wonders of modern technology and information and communication technology, that such a record is still not available.*

*The commission believes that an electronic health record for each Australian is one of the most important systemic opportunities we have. It would improve continuity, safety, reduce errors and duplication and promote best care.*

*An electronic health record that can be accessed, with a person's agreement, by health professionals across all settings is arguably the single most important enabler of truly person-centred care.<sup>9</sup>*

Dr Christine Bennett, 2009.

In 2010, Minister for Health Nicola Roxon announced funding to implement the Personally Controlled Electronic Health Record. Legislation was passed in 2012 that governed the operation of the system.

*The central theme of our system and this bill is that any Australian will be able to register for an e-health record, and they will be able to choose the settings for who can access their record and the extent of that access. ...*

*A registration framework will ensure regulation of all these parties, verification of identity, assurance that minimum technical, security and administrative requirements are met, and system accountability. The bill prescribes the circumstances in which e-health record information can be collected, used or disclosed and imposes civil penalties for knowing or reckless unauthorised collection, use or disclosure. ...*

*We are establishing new consent settings for sensitive information and auditing that does not currently exist for an individual's health record.<sup>10</sup>*

Minister for Health Nicola Roxon, Hansard, 23 November 2011

The decision was welcomed by clinical, consumer and industry groups.

*I am writing on behalf of the Business Council of Australia (BCA) which represents the CEOs of Australia's top 100 companies to advise you of our support for early commitment by COAG and the Commonwealth government to implementation of the national e-health strategy.*

*The BCA has been promoting the need for reform of the health system and for sustained improvement in Australia's health status as an integral part of the productivity and workforce participation improvement strategies necessary to underpin Australia's future economic prosperity. We have become convinced that acceleration of a nationally integrated e-health system is fundamental to achieving these reforms.*

Katie Lahey, Chief Executive Officer BCA, 2010.<sup>11</sup>

The system commenced operation in July 2012, following significant consultation with clinicians, consumer groups and industry.

*With the national eHealth record system in place, we now have for the first time a secure way for patients to share their health information with their healthcare providers – with the patient controlling the information and which healthcare providers can have access to the record.*

*I am proud to be associated with such an important reform initiative that will improve clinical outcomes and have such an impact on the future health of all Australians.*

David Gonski AC, Chair National eHealth Transition Authority, Annual Report, 2012/13

Consumers could 'opt-in' to have a record through the following channels:

- **Online** by logging into MyGov, creating a Personally Controlled Electronic Health Record and authenticating by providing information known to Medicare such as details of their last GP visit;
- **By phone** by establishing their identity by providing information known to Medicare;
- **In person** at a Medicare office; or
- **In person** through 'assisted registration' by a healthcare provider such as their GP.

## **(a) The expected benefits of the My Health Record system**

Australia's health system is among the best, most accessible and most efficient in the world. However, we face many challenges. There is evidence that approximately two million adverse drug events (ADEs) occur every year in Australia<sup>12</sup>, with an estimated 230 000 ADEs leading to hospitalisation.<sup>13</sup> Over 2000 deaths in Australia each year are related to medication errors.<sup>14</sup> This not only effects the safety and quality of care for patients, it is estimated ADEs cost taxpayers more than \$1 billion annually. It is also estimated that 14% of pathology tests are ordered due to lack of access to patients' history.<sup>15</sup>

Almost four million Australians (16% of the population) see more than three different health professionals for the same condition. Of those, one in eight (13%) reported that there were issues caused by a lack of communication between their health professionals.<sup>16</sup>

Evidence shows that these challenges will be addressed by safely and seamlessly sharing high quality clinical information between healthcare providers.<sup>17 18 19</sup> As a critical mass of people and healthcare providers use the My Health Record system, Australia's national health system becomes better connected

and integrated. The result is: safer, faster and more efficient care for people and their families; a person-centred and more sustainable healthcare system; and improvements in health outcomes through seamless sharing of patient health information.

The My Health Record benefits model is built on local and international experience of critical success factors for national digital health systems, and recognises that end benefits for consumers and providers can only be delivered when certain conditions are met:

1. An individual needs to have a My Health Record;
2. An individual's record needs to be populated with relevant information by registered healthcare providers with connected systems that are automatically or manually uploading health information; and
3. Healthcare providers are viewing My Health Record information, and that a change their course of action results in one of the defined end benefits being achieved.

The Agency is working to ensure that all of these elements are in place in order to deliver and measure the health benefits.

The Agency has established a comprehensive program of real world Australian research in partnership with academia and jurisdictional colleagues to measure the benefits of the My Health Record system. The intention is to provide robust evidence to demonstrate both health benefits and health budget savings.

*I accept that some individuals may have concerns about their My Health Record and these people have the choice to opt out. I haven't opted out. I believe that as a consumer I will personally benefit by having a My Health Record.*

WA Health Minister Roger Cook<sup>20</sup>

Currently, more than 6 million individuals have a My Health Record. These individuals are already realising the benefits of the system.

- A recent study<sup>21</sup> showed that 61% of general practitioners and 79% of pharmacists who have used My Health Record are reporting that they have experienced or observed one or more actual benefits from use.
- The most common benefits for general practitioners are being able to view a patient's health information that was previously unknown (36%), and saving time requesting information (33%).
- 29% of pharmacists who have used My Health Record reported avoiding a potential adverse medicines event by having access to a patient's medicines information.

As well as reporting actual benefits, there is agreement amongst healthcare providers of the potential for My Health Record benefits if registration is rolled out to the majority of Australians through an opt-out participation model. A very high proportion of providers who have actually used My Health Record agree that the system has the potential to improve access to patients' information (93%), reduce adverse medicines events (87%), and reduce the need to order pathology and diagnostic imaging (83%).

*I'm a GP. I have a My Health Record and so do my children and husband. I know that it can make your care more streamlined; that you will repeat fewer tests; that you and those providing your healthcare will know more about what has happened to you. I know it can save your life.*

Dr Ines Rio, a GP and chair of North Western Melbourne Primary Health Network<sup>22</sup>

Additional views from clinicians are at **Attachment A**.

The optimism that healthcare providers have in the utility of the My Health Record has also been reflected through their professional and peak bodies. The Australian Medical Association says the My Health Record "is the future". National Rural Health Alliance CEO Mark Diamond said "simply put, My Health Record can save lives"<sup>23</sup> while the Cancer Council of Australia said "the My Health Record has many benefits including helping consumers become more proactive participants in the management of their own health."

Distinguished Research Professor Fiona Stanley said the My Health Record is a "win for the health and wellbeing of the whole community, as those of us passionate about evaluation and improving outcomes will have the best data on the total population to conduct such vital research".<sup>24</sup>

The My Health Record also supports a number of national health strategic plans to improve healthcare outcomes in key priority areas for Australia such as Aboriginal and Torres Strait Islander health, diabetes and mental health, and improving health service delivery for people in regional and rural Australia. The role of the My Health Record in helping to deliver on the vision and objectives of key national healthcare strategic plans, refer to **Attachment B**.

### **Helping healthcare providers get the most out of the My Health Record**

Since it was established, the My Health Record has continued to grow in its capability, usability and integration with clinical information systems across the health sector.

Software organisations have made significant advances to make it easier to find documents and access medicines information, as well as pathology and diagnostic imaging results through new views recently added to My Health Record. For instance, the “Medicines View” is a recent addition that has been applauded by clinicians using My Health Record. It provides a consolidated summary of the most recent medicines information from notes entered by GPs, hospitals, pharmacies and consumers, allowing previously siloed medicines information to be brought together into a single view.

Searching for documents is easier, there are improved sorting and filtering options, and the authoring of health summaries and event summaries has been simplified. To make the most out of the system, it is important that providers keep up-to-date with the latest version of their Clinical Information System.

In addition to improvements in the features of My Health Record for people and clinicians, the system has undergone a significant transformation in terms of the richness of its clinical content. Public and private pathology and imaging providers are now connecting to the system, and there has been a vast increase in connected pharmacy systems as well as hospitals around the country. The addition of this valuable clinical content will accelerate the realisation of benefits as clinicians find that they now have access to a more comprehensive source of information within the My Health Record system.

### **(b) The decision to shift from opt-in to opt-out**

This year, the Agency is ensuring that every Australian will receive a My Health Record unless they choose not to have one. This is referred to as the My Health Record Expansion Program, and it involves transitioning from ‘opt in’ to an ‘opt out’ participation model.

The decision to shift from an opt-in participation model to opt-out was a decision for the Australian Government, which was:

- Recommended by an independent review of the My Health Record system in 2013;
- Given bipartisan support when it was considered by the Parliament (including a Senate Inquiry) and passed by both houses without amendment or division on 12 November 2015; and
- Informed by the independent evaluation of the My Health Record Participation Trials, which found almost universal support for opt-out.

The Personally Controlled eHealth Record (PCEHR) was established in 2012 with the principle of consumer participation and control built into the system design. While originally established as an opt-in registration model, under an opt-out participation model, the original principles still apply: people have the right to participate but can choose not to, and the record is truly personally controlled.

### **Review of Personally Controlled Electronic Health Record**

After 1.5 years of operation, Minister for Health Peter Dutton announced an independent review led by Richard Royle into the implementation of the PCEHR. The review panel presented its [report](#) in December 2013 and called for changes to the implementation strategy:

*Overwhelming support was found for continuing the path of implementing a consistent electronic health record for all Australians. A change in approach however is needed to correct early implementation issues and to review the strategy and role that a shared electronic health record plays in a broader system of health care. Future focus must see the electronic health record (and associated technical and data foundations) as a fundamental element of our future Health infrastructure and it is the Panel’s view that with intervention and correction, the investment will realise great value for the health industry over time.*

Review of the PCEHR, December 2013<sup>25</sup>

The Review reaffirmed the experience in the Northern Territory of three critical success factors; high levels of consumer participation, active use by healthcare providers across all parts of the health sector, and sufficient clinical content to make accessing the system worthwhile.

The Review recommended that the system move to opt-out. It noted significant challenges with the opt-in process to date, including a lack of focus on those in most need of an electronic health record such as people with chronic medical conditions or living in remote areas. Moving to opt-out would ensure:

- 'healthy' consumers who might not have signed up would be more likely to have a record, which would be of value when they experienced an illness or injury that necessitated acute or ongoing treatment;
- vulnerable and disadvantaged consumers would not face the obstacles to opting-in; and
- mechanisms would still be in place to support consumer choice; with consumers able to opt out or apply consumer access controls.

The Review also recommended a program to raise awareness and use of the system by healthcare providers, and to increase the amount of clinical content in the system. It also recommended the system be renamed the My Health Record.

*Considering the current stage of the PCEHR roll-out and the lack of meaningful usage of the record, CHF reiterates its view that the PCEHR system will be more successful if it is to be opt-out, rather than opt-in. Our extensive consultation with consumers, consideration of the positions of other key stakeholder groups and review of international experience support and consolidate this position.*

Consumer Health Forum, quoted in Review of PCEHR, December 2013<sup>26</sup>

### **My Health Record and opt out trials**

The Government responded to the Review by renaming the system the My Health Record and announcing that it would trial opt-out participation in two regions with two opt-in regions as a control in 2016, with a decision about national opt-out to be informed by the experience in these trials.

The *Health Legislation Amendment (eHealth) Bill 2015* was introduced to the Australian Parliament to enable opt-out participation trials and allow for the extension of opt-out arrangements nationally in the future.

*If the trials provide evidence that an opt-out system is a better approach for improving participation in the My Health Record system, the bill provides the ability for the government to extend opt-out arrangements nationally, in consultation with the states and territories.*

Minister for Health Sussan Ley, Hansard, 17 September 2015

The Bill received bipartisan support in the House of Representatives.

*The most significant change is the move to increase the number of electronic health records by moving to an opt-out system where all Australians will be given electronic health records unless they specifically choose not to have one. Sensibly, the government has accepted the recommendation to commence this process through trials.*

Shadow Minister for Health, Catherine King, Hansard, 14 October 2015

After the Bill passed the House of Representatives, the Senate referred the provisions of the legislation to the Senate Community Affairs Legislation Committee for inquiry on 15 October 2015. The Committee recommended the Senate pass the Bill, and the legislation was passed by the Senate without amendment or division on 12 November 2015.

The opt-out trials were conducted from March to October 2016 in Northern Queensland and the Nepean Blue Mountains region in New South Wales. To understand consumer reaction to different participation arrangements, as well as healthcare provider usage and upload of clinical information to the patients' records, different approaches to opt-in were also trialled in Western Australia and Victoria.

The participation trials [evaluation](#) found "overwhelming and almost unanimous support" for an opt-out system and recommended the adoption of opt-out arrangements nationally.



*For both individuals and healthcare providers interviewed there is a high level of support for the automatic creation of My Health Records. For healthcare providers, the burden of assisted registration is seen as a major impost that is not practical without additional funding. There is also a belief that, even if these additional resources were available, they would be unsustainable in the health system or could be better used for direct health service delivery.*

*For most individuals, after automatic creation was explained and the benefits of the My Health Record system were understood, the sentiment was positive. They said the fact that they did not have to do anything to create their My Health Record was a major plus. They expressed the view that they would not have registered for a My Health Record themselves and would have expected that their healthcare providers already would be sharing information with other healthcare providers in this way.*

*Based on data from all sources available to the evaluation, a national opt-out approach is not only acceptable to individuals, healthcare providers, participating health service and health department managers, it is seen by these participants as the only sustainable and scalable approach.*

Evaluation of the Participation Trials for My Health Record, November 2016.<sup>27</sup>

## Community support

Support to move to an opt-out arrangement has come from across the community from people who see the benefits of the My Health Record.

*As a mother of a child with a chronic illness, it gives me great comfort and assurance to know that wherever he goes, his complex medical history including an allergy will be available at the point of care with My Health Record to ensure that he gets the right care. It can be there when I'm not.*

Consumer, Sydney

*For people with complex disabilities who may have significant health needs, communication difficulties, and a limited ability to advocate for themselves, the introduction of a properly resourced, protected and simple My Health Record could significantly improve the timely treatment of people across the health system, and enable their personal wishes for treatment to be considered without suppositions and judgements being made by health professionals about quality of life or continued treatment.*

Kerry Stubbs, CEO Northcott Disability Services, Past winner of NSW Telstra Businesswoman of the Year Award Australian Digital Health Agency Consumer Advisory Committee<sup>28</sup>

*In my current role assessing patients prior to their surgery I have the complex task of collating information on medical history, medications, allergies, specialist reviews, and pathology and radiology reports which have been completed outside of my hospital. It can take hours or days until this information is faxed to my clinic once a request is sent, despite the need to make urgent decisions on fitness of patients to undergo anaesthesia. I have discussed this situation with many of my patients and they have all be supportive of the benefits that the My Health Record will bring. The benefits in my daily work will be immediate.*

Dr Rowan Ellis, Resident Medical Officer

People involved in the trials supported the system and saw its benefits.

*"I think it is an excellent idea because I live in a small town and have my treatment here and at one stage during my treatment I was in a different small town and I was critically ill and at that point if they could have accessed my records because I gave them the information and said you need to ring Ballarat they didn't and I nearly died...With my understanding of what this My Health Record is they would have been able to access my clinical history and everything might have been slightly different."*

*"I changed doctors... I wasn't happy with the doctor I had... When you go to talk to some doctors you don't get some support that you want... I think they get complacent... I looked around and found a new one and I am on the same level as him he doesn't talk down to me. He mentioned this My Health Record thing and I thought it was a good idea. When I was doing a lot of travelling I thought it would be great for this record being accessible by all healthcare providers... I am all for it – I think it's terrific."*

*"We do the grey nomad thing quite a bit and you know I have a chronic disease and it's just a pain having to remember everything and even all your scripts and that sort of thing. If I am not at home it just makes it harder to do everything to manage my conditions... So having this available to use would be really helpful for me and my wife."*

Additional views from consumers are in [video case studies](#) on the Agency website and at **Attachment C**.

## **(c) Privacy and security**

Australians expect strong safeguards to ensure their health information is safe and secure. The principles of the My Health Record consider the security and protection of sensitive personal health information, balanced with information sharing to support healthcare as critical to maintaining consumer and clinician trust.

### **(i) Concerns regarding the vulnerability of the system to unauthorised access**

To protect sensitive health data stored in the My Health Record system, the Agency employs multiple layers of security to protect the system from malicious attack. This approach, known as defence in depth, is based on the idea that any single method of defence can be bypassed, so it is important to implement a range of security measures that work simultaneously to protect our critical data. The system has been built and tested to Australian Government standards to protect the confidentiality, integrity, and availability of the health records.

The My Health Record System has been certified and accredited under the Australian Government Information Security Manual. These capabilities include comprehensive security monitoring; strong process and technology security controls; security assurance for all new releases; and dedicated security operations management.

Continuous improvements in the cyber security environment help ensure that the security of the My Health Record is maintained and constantly improved.

The security measures employed by the Agency include:

- Policies, procedures, awareness – having appropriate security policies and procedures facilitates a consistent approach to security, and coupled with a strong focus on building security awareness, this provides our first layer of defence.
- Physical security – a range of physical security measures, such as swipe card access control, appropriate building design, robust locking mechanisms, cameras and alarms provide the next layer of defence.
- Perimeter – we have security measures to protect the perimeter of our network, such as firewalls with appropriate filtering rules, border routers, demilitarized zone (DMZ), and virtual private networks (VPNs).
- Internal network – a range of security controls are implemented to protect our internal network. This includes network segmentation, encryption measures to protect data in transit, network monitoring and analysis, network access control and authentication, and in-line malicious content filtering.
- Host – a number of host-based protective measures are used to provide additional protection, including host-based anti-virus protection, host-based access control and authentication, port control, patch management processes, security information and event monitoring, host hardening, measures to prevent direct access to the host (lockdown mode), vulnerability management solutions, host-based firewall, host-based intrusion detection and intrusion prevention systems and file integrity monitoring.
- Application – strong authentication and access control measures, input validation, content filtering software, and application hardening.
- Data – the final layer of defence is the data layer, where protective measures are applied to the data itself, such as encryption to protect data at rest; a strong backup and recovery regime; and tightly controlled access provisions for the data itself.

In addition, a number of security assurance activities are applied to ensure the security of the My Health Record system is adequately maintained, including:

- Accreditation of the system in accordance with the Australian Government Information Security Manual (ISM) and Protective Security Policy Framework (PSPF). These assessments are undertaken by an independent assessor, in line with the Australian Government InfoSec Registered Assessors Program (IRAP).
- Threat and risk assessments that independently audit the effectiveness of security controls.
- Regular penetration testing, to understand and monitor security threats, risks and vulnerabilities.



- Continuous improvement of security measures using an internationally recognised framework (ITIL) to mitigate risks in a timely manner.
- Pre-release testing to identify and rectify any security vulnerabilities, prior to release of new system functionality.
- Engaging with Australian Government security agencies and health sector organisations in relation to security issues, to assist with improved security awareness and maturity, particularly for systems used to access the My Health Record system.
- Ensuring personnel involved with management of the My Health Record system have a baseline security clearance, granted by the Australian Government Security Vetting Agency.
- The process for assessing and managing security risks associated with the My Health Record system is based on a number of well-known international standards, including:
  - Information security policies and supporting standards based on the International Standards Organisation (ISO) information security standards (ISO 27000 series); and
  - Risk assessments conducted according to the Agency's risk management framework, which is based on the international risk management standard (ISO 31000).

Systems connecting to the My Health system must pass strict conformance requirements before the Agency allows them to connect. Healthcare provider organisations connect to the My Health Record through conformant software which has a secure and encrypted connection to the My Health Record. Healthcare provider access requires two factor authentication; through a NASH or a PRODA security certificate issued by the Department of Human Services, and through their local authentication method (usually a username and password).

### **Privacy Protections in the My Health Record System**

The Agency welcomes the public discussion that has taken place in respect to community concerns around privacy. Our objective is to ensure that Australians are able to understand how the system works so they can make an informed choice about having a My Health Record.

The My Health Record system is a world-first national system in enabling consumers to access their own record, control what information is in their record and control which healthcare provider organisations it is shared with. Individuals have a number of options to manage their privacy:

- An individual can opt out of having a record.
- An individual can ask a healthcare provider to not upload information and the healthcare provider must comply.
- An individual can place a Record Access Code on their record so that they have to provide a healthcare provider organisation with the code before the provider can access the record.
- An individual can place a Limited Document Access Code to restrict access to specific documents relating to visits to healthcare providers, or medicines they are taking, such that they have to provide the code for the health care provider organisation to access the document.
- An individual can choose to be notified via an SMS alert or email in real time when their record is accessed for the first time by a healthcare provider organisation, or when other actions occur such as a shared health summary being uploaded or where emergency access has been made.
- An individual can remove documents from view from the system.
- An individual can see a full history of all access to their MHR, and are able to contact the Agency to get more information about these accesses.
- An individual can cancel their record at any time which ensures a healthcare provider can no longer access the information in the record.

There are two mechanisms by which a healthcare provider can view an individual patient's My Health Record, both of which have robust authentication processes in place, through the National Provider Portal or through a Clinical Information System, both of which are explained below.

To access the MHR system through the National Provider Portal, the healthcare provider needs to:

- have an individually assigned Healthcare Provider Identifier - Individual (HPI-I);

- work within an organisation that has registered for and received a Healthcare Provider Identifier - Organisation (HPI-O);
- have a secure and encrypted connection to the My Health Record system; and
- provide the name, Medicare card number, gender and date of birth of the individual whose record they are trying to access.

To access the My Health Record system through the Clinical Information System, the healthcare provider needs to:

- be using conformant software which has a secure and encrypted connection to the My Health Record system;
- be authorised to access the system by the healthcare provider organisation; and
- be providing healthcare to a patient of the practice who has had a record created on the local Clinical Information System (with patient name, Medicare card number, date of birth and gender as part of the local record).

These safeguards are in place to ensure that only members of the patient's healthcare team who are authorised and are treating a person are able to access a record. Furthermore, the healthcare provider organisation must be registered in the My Health Record system.

A healthcare provider is only authorised to access a consumer's record in the course of providing them healthcare. The common statement that 'anyone who has ever provided a consumer with healthcare is able to access your record' is untrue. Administrative staff — or any other staff — who are not involved in providing healthcare are not permitted to access the My Health Record system. Unauthorised collection, use or disclosure of My Health Record information by an individual is subject to a custodial prison sentence of up to two years and fines of \$25,200 (criminal) or \$126,000 (civil) for each offence.

The access by the healthcare provider organisation will be logged in the patient's My Health Record. If an individual or corporation were to misuse information in the My Health Record system they would be subject to criminal and civil penalties.

Concerns have also been raised that information would continue to be stored for people who have cancelled their My Health Record. Currently under section 17 of the My Health Records Act, the System Operator is required to retain this information until 30 years after the person's death. This information was determined to be held for various reasons, including to provide for medico-legal needs and to reflect Commonwealth record keeping requirements.

The Government has listened to community concerns expressed around privacy — and particularly any possibility of police access without court order and the status of a cancelled record being retained after deletion. The Minister for Health has announced his intention to change legislation on these matters, and as the System Operator, we will implement any changes to legislation passed by parliament. These changes acknowledge the evolving expectations of the community since the legislation was first debated and approved in Parliament in 2012, and the willingness to listen and to deliver a My Health Record system that supports all Australians to have better and safer health care.

The changes also reflect the strong and positive advocacy of the clinical and consumer peak bodies who have been central in advocating for these issues to be addressed in the legislation.

#### **(ii) The arrangements for third party access by law enforcement, government agencies, researchers and commercial interests**

Since the opt-out period began, concerns have been expressed by some healthcare consumers, privacy advocates and some peak healthcare bodies about the provisions of the My Health Record Act that authorise the release of information by the System Operator.

Over the entire period the Agency has been operating the My Health Record, we have never received a request for information for law enforcement purposes and have not released any information for such purposes. The Agency has an operational policy that it would not release any documents without a court or similar order.

#### **(iii) Arrangements to exclude third party access, including employers or insurers**

Concerns have been raised in the community that insurance companies may be able to access an individual's My Health Record to set premiums, or that employers could get access to their employees'

record through employer appointed healthcare professionals. These actions are specifically prohibited under the governing legislation as explained below.

Under the *Healthcare Identifiers Act 2010*, subsection 14(2), healthcare providers cannot be authorised to collect, use or disclose a healthcare identifier, and as a consequence access a patient's My Health Record, for employment and insurance purposes. Under the Act it is expressly prohibited and using or disclosing a healthcare identifier without authority is an offence and subject to severe penalties, including two years in prison and a fine of \$126,000 for individuals.

An insurance company that also provides a health service (e.g. optical, dental, allied health services) could become a participating healthcare organisation and access the My Health Record as part of providing care to patients. However, the healthcare service of the insurance company is prohibited from sharing an individual's health information with any other part of the insurance company that is not directly involved in providing healthcare to the individual.

It is also important to note that the Australian health insurance system is a 'community rating' system, which means that everyone pays the same premium for their health insurance and health funds are prevented from discriminating against members on the basis of health status, age or claims history.

## **(d) The Government's administration of the My Health Record system roll-out**

### **The My Health Record Expansion Program**

To deliver a My Health Record to every single Australian unless they choose not to have one by December 2018, the Agency established the My Health Record Expansion Program. The Agency identified four priority outcomes that need to be delivered by the Program:

- Consumers can opt out efficiently or have a record created;
- Consumers can participate with a high quality of service;
- Healthcare providers have access to the required My Health Record functionality and have been adequately educated to meet consumer expectations about their awareness of the My Health Record; and
- Back end systems are robust and stable.

The 2016 opt out trials provided important lessons about communicating with consumers:

*I remember seeing in the brochure or a letter – that as you control it you can delete things you don't want to be on there. Consumer, Springwood, NSW*

*I first heard about it in the neurology clinic, saw it as a poster. I thought it was something for only the doctors so they could share information. Consumer, Cairns, QLD*

*It needs to be a demographic rollout. What you just said is great for people who go and see their GP. But for, and I am really stereotypical here.... but for your younger generation if it is not on Facebook or Instagram they will not even know it exists. Consumer, Penrith, NSW*

The national communications plan considered key findings from the trials:

- General consumer awareness should be raised by a nationally co-ordinated, but locally run communications campaign;
- Consumers were most receptive to messages about the My Health Record when they were in a healthcare setting, compared with mass communication such as letters sent to every household;
- Once aware of the My Health Record, consumers often sought more information or an opinion about the system from their healthcare provider – typically their GP or pharmacist; and
- It was a mistake to commence the public communications campaign before the opt out period had started, as some consumers wanted to opt out immediately but were unable to, and others dismissed the message because they were unable to act on it for another 4-6 weeks.

The communications plan for national opt out therefore included:

- Focussing on healthcare provider awareness first. Providers were informed through multiple channels about the My Health Record and the opt out process from November 2017 onwards. This would equip healthcare providers with information to respond to the most common enquires from consumers and know where to send consumers for more information;
- Placing consumer messages about the My Health Record in healthcare settings, such as GP practices, community pharmacy and hospitals;
- Designing a nationally driven but locally supported campaign – where messages and collateral were developed centrally, but media strategies and advertising were run at a local level;
- Focussing messaging on what the My Health Record was and assisting consumers to make an informed decision about whether to opt out, including publishing information and videos on the Agency website on how to set privacy controls;
- Commencing the consumer communications campaign when consumers could opt out – and not before – to better support consumers to exercise their choice as soon as they heard the message.

The program allocated \$27.5 million to raise consumer awareness about opting out.

The resulting communication plan aims to provide an individual a 10+ opportunity to see My Health Record and opt-out messaging across the opt-out period. These opportunities span across six broad areas including health settings, community, digital, advocacy, advertising and publicity.

This included over 127 million social accounts reached with over 127,000 pieces of content posted creating 925 million opportunities to see, delivery of over 1,300 community events, and more than 7000 paid advertising placements.

It also involved 5,067 pieces of traditional media content published in the press, radio and TV. This reached a cumulative audience (opportunity to see the content) approaching 200 million times, including:

- Television 48.2 million opportunities to see, with a peak day of 18.1 million;
- AM Radio 64.0 million opportunities to hear, with a peak day of 12.2 million;
- FM Radio 13.6 million opportunities to hear, with a peak day of 4.6 million; and
- Newspapers 43.3 million opportunities to see, with a peak day of 3.4 million.

Tracking research as of 3 September 2018 shows that awareness of My Health Record has increased to 87%, and awareness that every Australian will get a My Health Record unless they tell us they don't want one has increased significantly since the beginning of the opt-out period, from a pre-benchmark of 16% to 59%. Research is conducted by ORC International via a CATI survey with 1000 people weekly. The sample size is statistically representative of the Australian population.

More than 1.5 million people have visited the MHR website since the commencement of the consumer awareness campaign. The percentage of new visitors (>81%) and the bounce/exit rate is high (>29%) indicating that people have found the information they needed.

### Results of the communications campaign

The key aggregate information shown below demonstrates the extent of community outreach that Agency has delivered in partnership with its partners in the community:

MyHealthRecord.gov.au website	<ul style="list-style-type: none"> <li>• More than one and a half million people visited the My Health Record website following the interest and publicity in the media</li> <li>• The % of NEW visitors (&gt;81%) and the bounce/exit rate is also HIGH (&gt;29%) indicating that people found the information they needed to make an informed decision</li> <li>• 2,800 email requests were sent to the My Health Record inbox</li> </ul>
Social media	<ul style="list-style-type: none"> <li>• There were over 925 million opportunities to see social media content (impressions)</li> <li>• More than 80 million confirmed social media accounts within Australia had opportunity to see social media content (people have more than one type of social account hence the number is higher than the population)</li> <li>• 127 thousand pieces of content were posted from more than 21 thousand authors</li> </ul>

MyHealthRecord.gov.au website	<ul style="list-style-type: none"> <li>• More than one and a half million people visited the My Health Record website following the interest and publicity in the media</li> <li>• The % of NEW visitors (&gt;81%) and the bounce/exit rate is also HIGH (&gt;29%) indicating that people found the information they needed to make an informed decision</li> <li>• 2,800 email requests were sent to the My Health Record inbox</li> </ul>
Traditional media	<ul style="list-style-type: none"> <li>• 5,067 pieces of traditional media content was published from Press, Radio &amp; TV. This reached a cumulative audience (opportunity to see the content) of 173,099,357 million times</li> <li>• Television: 48.2 million opportunities to see, with a peak day of 18.1 million</li> <li>• AM Radio: 64.0 million opportunities to hear, with a peak day of 12.2 million</li> <li>• FM Radio: 13.6 million opportunities to hear, with a peak day of 4.6 million</li> <li>• Newspapers: 43.3 million opportunities to see, with a peak day of 3.4 million</li> </ul>
Events and sentiment	<ul style="list-style-type: none"> <li>• Information is now available in over 15,000 health care locations including general practices, pharmacies, public and private hospitals, and via Aboriginal Medical Services and National Aboriginal Community Controlled Health Organisations</li> <li>• 1,384 events were completed through Primary Health Networks reaching 2 million people</li> <li>• 1,945 consumer surveys completed showing 86% awareness that they would have a My Health Record created for them in 2018 and more than 64% positive about this</li> <li>• 126 provider surveys completed showing 95% awareness that people will have a My Health Record created for them in 2018 and more than 69% positive about this. 62% likely to view a patient's My Health Record, 58% likely to upload, 66% likely to recommend</li> <li>• 4,000 computer assisted telephone interviews (CATI) conducted with the most recent wave (1,000 calls) revealing that 56% have heard they are getting a My Health Record and 51% are aware they can opt out</li> </ul>

There will be ongoing awareness and education occurring post the opt-out period to help educate the majority of Australians that they will have a record created by the end of this year, including younger Australians. There will also be ongoing education and support provided to healthcare providers, with additional focus on allied health professionals and specialists, to support their use of the My Health Record system and helping their patients to manage their health information.

The publicity and media attention created during the opt-out period enabled significant outreach to the public to supplement the Agency's paid advertising. The national conversation supported the program's aim that every Australian be informed and have the opportunity to opt-out of the My Health Record system if that is their wish.

Furthermore, the positive stories of My Health Record are being heard with people discussing why they are choosing to not opt out. This positivity is also demonstrated by the significant increase in consumers registering for a My Health Record since the opt-out period began – Between January 2018 and the commencement of the opt-out period on July 16, the average consumer registration rate was an average 17,848 consumers per week. The average consumer registration rate during the opt out period has increased by over 40% to 25,254 consumers per week.

## **(e) Measures that are necessary to address community privacy concerns in the My Health Record system**

The national consultation to deliver a national digital health strategy for Australia found that health consumers and carers have a clear expectation that the privacy of their health information should be respected, and their rights protected. Australians expect strong safeguards to ensure their health information is safe and secure, and that their data is used only when necessary and when they choose.

Clinicians and healthcare providers told us they need assurance that the digital systems they use support them to meet their obligations to keep their patients' health information private, and that health data will be used safely and appropriately to improve patient outcomes. The Agency understands that healthcare

information is some of the most private information people have, and that the success of Australia's digital health program is reliant on secure digital operations and respecting people's rights to privacy.

### **My Health Record data breaches**

The Office of the Australian Information Commissioner (OAIC) is assigned a regulatory oversight role in the My Health Records Act, which is administered under a Memorandum of Understanding (MoU) with the Agency.

Under section 75 of the Act, the System Operator has an obligation to notify the OAIC of certain data breaches. Data breaches are also described in section 75, which requires those entities to notify the OAIC as soon as practicable where there has or may have been:

- unauthorised collection, use or disclosure of health information included in a My Health Record; or
- events or circumstances that compromise, may compromise, have compromised or may have compromised, the security or integrity of the My Health Record system. This covers circumstances where there was the potential for unauthorised access to data but the access did not actually occur.

Under the My Health Records Act, the obligation to notify the OAIC is triggered when there has or may have been a data breach. The OAIC then considers whether the circumstances warrant opening an investigation, or whether to provide advice about further steps the entity could take in relation to the breach. To date no such investigations have been opened.

Security breaches are a type of data breach where the system or data is accessed by bypassing the security controls in place, for example if a person were to break the authentication controls and gain access to a record. This has not occurred during operation of the My Health Record system.

The 2016-17 OAIC report contains details of six System Operator reported data breaches. Of the six, four were the result of unauthorised access which stemmed from alleged fraud against Medicare. The alleged fraud occurred as a result of a third party logging onto myGov and submitting fraudulent Medicare claims. As a result, there was an opportunity for the fraudulent claimer to also click on other services in myGov, including the My Health Record which is available through the myGov portal. While there was the potential for unauthorised access to occur, there is no evidence that this actually occurred. The incorrect Medicare records were removed from the consumer's My Health Record, and the myGov account links were disconnected.

The two remaining breaches reported were the result of a child being added to the incorrect Medicare card, and a consumer then seeing the existence of that My Health Record. Both instances were due to a processing error whereby a baby was incorrectly linked to the wrong parent in the Medicare system, which then incorrectly assigned that parent as the Parental Authorised Representative of a newborn child that was not known to them. Both breaches occurred due to a processing error of the FA081 form by DHS. The FA081 form is used to register a newborn for Medicare and a My Health Record. In both situations, the incorrect Parental Authorised Representative of the newborn was able to view the demographics (name, address, date of birth, age, individual healthcare identifier) and Medicare information of the newborn when the consumer logged onto their My Health Record. No health information of the newborn was viewed.

There is no evidence that an unauthorised person actually viewed any health information in the My Health Record; only demographic information such as name and date of birth was viewed. To resolve the matter, the links were changed to the correct Parental Authorised Representative.

For responses to other community privacy concerns, refer to **Attachment D**.

## **(f) How My Health Record compares to alternative systems of digitising health records internationally**

There are as many different models of digital health around the world as there are healthcare systems, and there have been a wide variety of approaches. Digital health policy implementation has been strongly shaped by the type of government institutions and policy frameworks of each country, as well as local health, social welfare, telecommunications needs, and a variety of stakeholders. These factors can also determine the pace of change and maturity within health systems.

A key feature of Australia's national electronic health record system is that patients have access to and can control what is stored on their health records and decide which healthcare providers can view or add to their files – this is a feature which sets Australia apart from other countries.

International examples of national electronic health records with opt-out consumer participation arrangements are summarised below.

### **United Kingdom**

#### *National Health Service's (NHS) Summary Care Record*

A Summary Care Record (SCR) is an electronic patient record, a summary of National Health Service patient data held on a central database covering England, part of the NHS National Programme for IT.

If a patient is registered with a GP practice in England then their SCR is created automatically, unless they have opted out. 98% of practices are now using the system. Once entered and viewed, records cannot be fully deleted. Patients can opt-out and request for their information to be withheld from the SCR. In the period June 2018 to July 2018 patients aged 13 and over received a letter to inform them about the conversion of their "type 2" opt-out. Some patients will have registered a "type 2" opt-out with their GP practice, to prevent their confidential patient information from leaving NHS Digital for purposes beyond their individual care.

The SCR can be viewed by health and care staff, and viewing is now being rolled out to community pharmacies. SCRs can be viewed through clinical systems or through the SCR web viewer, from a machine logged in to the secure NHS network, using a smartcard with the appropriate Role Based Access Control codes set.

Data within the SCR is protected by secure technology. Each use is recorded. A patient can ask to see the record of who has looked at their SCR, from the viewing organisation. This is called a 'Subject Access Request'. Patient data is protected by strict information governance rules and procedures. Each organisation using the SCR has at least one privacy officer who is responsible for monitoring access and can generate audits and reports.<sup>29</sup>

### **Austria**

#### *Elektronische Gesundheitsakte (ELGA)*

ELGA is an information system which provides consumers and their treating doctors, hospitals, care facilities and pharmacies with easy access to their health records. Health records such as medical reports on a person are created at various health facilities. ELGA networks this data and makes it available electronically via a link.

The underlying legal basis (federal ELGA-law) was enacted by the Austrian parliament in 2013 and includes regulations to the participation of citizens (opt-out policy), the participation of healthcare providers (mandatory), data protection and security, provisions to the quality of documents in ELGA (mandatory Implementation Guides for ELGA content) and timelines for the rollout. ELGA is available to everyone who is covered by the Austrian health care system. Austrians can opt out of it online via the ELGA web page or in writing to the ELGA objections office. The current patient opt-out rate is about 3% and 4.2 million people – about half of the Austrian population – have already had contact with ELGA since go-live.

Use-cases of ELGA are basic infrastructure components like patient identification and demographics, authentication of healthcare service provider and patient, access control and logging and include the first two "ELGA application" use-cases operating on the infrastructure: "e-Reports", the sharing of clinical documents (Discharge Summary, Radio report, Lab report) and "e-Medication", the a medication list of prescribed and dispensed medication for each patient.<sup>30</sup>



## Estonia

### The Electronic Health Record (e-Health Record)

The e-Health Record is a nationwide system integrating data from Estonia's different healthcare providers to create a common record every patient can access online. Every Estonian is automatically included in the system from birth, and all are able to decline participation or 'opt-out' of the system. According to the most recent statistics, 687 people had their data closed off to doctors at some point during 2018. That makes up roughly 0.05% of the Estonian population.

40% of the population (500k) have used the system. System usage goes up every year and averages about 1.8 million queries by patients per month according to the most recent statistics (2 years ago they had about 800 000 queries per month).

Citizens can close off data to all doctors or specific doctors. They can block either all of their medical data or only a part of it (e.g. a certain doctor's visit). They can also grant access to their health data to other citizens (such as a caretaker, a sibling etc). They cannot edit or author parts of their health record, nor can they delete any health records. Estonia is looking into ways that patients can report certain health data themselves (e.g. blood sugar values).

For assuring the integrity of retrieved electronic medical records as well as system access logs, blockchain technology is being tested and will be implemented in the near future.<sup>31</sup>

## Attachments

- Attachment A: Clinician perspectives
- Attachment B: The role of the My Health Record in national healthcare strategic plans
- Attachment C: Consumer perspectives
- Attachment D: My Health Record: Misconceptions and Frequently Asked Questions

## References

- 
- <sup>1</sup> National eHealth and Information Principle Committee (2008)  
[http://www.health.gov.au/internet/main/publishing.nsf/content/69B9E01747B836DCCA257BF0001DC5CC/\\$File/National%20eHealth%20Strategy%20final.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/69B9E01747B836DCCA257BF0001DC5CC/$File/National%20eHealth%20Strategy%20final.pdf), pp.50-51.
  - <sup>2</sup> Halverson, G.C (2013) *Don't let health care bankrupt America: Strategies for financial survival*.
  - <sup>3</sup> National eHealth Transition Authority, 2015. *My eHealth Record to national eHealth record transition impact evaluation: Phase 1 evaluation report*. [https://www.digitalhealth.gov.au/about-the-agency/publications/reports/benefit-and-evaluation-reports/myehr-to-national-ehealth-record-transition-impact-evaluation-phase-1-report/TIE\\_Phase1\\_Report.pdf](https://www.digitalhealth.gov.au/about-the-agency/publications/reports/benefit-and-evaluation-reports/myehr-to-national-ehealth-record-transition-impact-evaluation-phase-1-report/TIE_Phase1_Report.pdf)
  - <sup>4</sup> World Health Organisation (2016). Global diffusion of eHealth: making universal health coverage achievable. Report of the third global survey on eHealth  
<http://apps.who.int/iris/bitstream/handle/10665/252529/9789241511780?sequence=1>
  - <sup>5</sup> Productivity Commission 2005, Australia's Health Workforce, Research Report, Canberra.  
<https://www.pc.gov.au/inquiries/completed/health-workforce/report/healthworkforce.pdf>
  - <sup>6</sup> Commonwealth of Australia (2010) Building a 21st Century Primary Health Care System, Australia's First National Primary Health Care Strategy,  
[http://www.nationalplanningcycles.org/sites/default/files/country\\_docs/Australia/6552\\_nphc\\_1205.pdf](http://www.nationalplanningcycles.org/sites/default/files/country_docs/Australia/6552_nphc_1205.pdf)
  - <sup>7</sup> Commonwealth of Australia (2009) Australia: The Healthiest Country by 2020 – National Preventative Health Strategy – the roadmap for action,  
<https://extranet.who.int/nutrition/gina/sites/default/files/AUS%202009%20National%20Preventative%20Health%20Strategy.pdf>
  - <sup>8</sup> National Health and Hospitals Reform Commission, 2009. A healthier future for all Australians: Final Report.  
[http://www.cotasa.org.au/cms\\_resources/documents/news/nhhrc\\_report.pdf](http://www.cotasa.org.au/cms_resources/documents/news/nhhrc_report.pdf)



**Australian Government**  
**Australian Digital Health Agency**

<sup>9</sup> Mark Methereill 'Just what the doctors ordered' in Sydney Morning Herald, 21 February 2009.

<https://www.smh.com.au/national/just-what-the-doctors-ordered-20090220-8doz.html>

<sup>10</sup> Nicola Roxon MP, House of Representatives, Australian Parliament, 'Personally Controlled Electronic Health Records Bill 2011', Second Reading, Hansard, 23 November 2011, Canberra.

<http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22chamber%2Fhansard%2F14965034-cdb8-4a26-98aa-26c862a1cd0e%2F0093%22>

<sup>11</sup> Katie Lahey, Business Council of Australia, (2010, Letter to the Shadow Minister for Health and Ageing, National e-Health Investment', 10 February 2012, [http://www.bca.com.au/docs/7BE5A38A-AC6B-4AF8-8F0C-6F196C570844/letter\\_to\\_the\\_shadow\\_minister\\_for\\_health\\_and\\_ageing\\_re\\_e-health\\_investment\\_final\\_4-2-2010.pdf](http://www.bca.com.au/docs/7BE5A38A-AC6B-4AF8-8F0C-6F196C570844/letter_to_the_shadow_minister_for_health_and_ageing_re_e-health_investment_final_4-2-2010.pdf)

<sup>12</sup> Roughead E, Lexchin J. Adverse drug events: counting is not enough, action is needed. Med J Aust. 2006;184(7):315-6.

<sup>13</sup> Roughead L, Semple S, Rosenfeld E. Literature Review: Medication Safety in Australia. Australian Commission on Safety and Quality in Health Care; 2013.

<sup>14</sup> Wilson RM, Runciman WB, Gibberd RW, Harrison BT, Newby L, Hamilton JD. The Quality in Australian Health Care Study. The Medical journal of Australia. 1995;163(9):458-71.

<sup>15</sup> Early cost and safety benefits of an inpatient electronic health record Zlabek et al J Am Med Inform Assoc (2011) 18 (2): 169-172

<sup>16</sup> Australian Bureau of Statistics. Patient Experiences in Australia: Summary of Findings, 2015-16. 4839.0 Canberra: Australian Bureau of Statistics; 2016 [Available from: <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4839.0>

<sup>17</sup> Georgiou A, Marks A, Braithwaite J, Westbrook JL. Gaps, disconnections, and discontinuities--the role of information exchange in the delivery of quality long-term care. The Gerontologist. 2013;53(5):770-9.

<sup>18</sup> Patient Safety Surveillance Unit. From Death We Learn 2015 Perth: Department of Health, Government of Western Australia; 2015 [Available from: <http://ww2.health.wa.gov.au/Reports-and-publications/From-Death-We-Learn>

<sup>19</sup> Health Care Complaints Commission. Case Studies, Volume 1. Sydney: Health Care Complaints Commission; 2003.

<sup>20</sup> Cathy O'Leary, 'Data fears may spark opt-out choice in WA from My Health Record, The West Australian, 9 September 2018, <https://thewest.com.au/news/health/data-fears-may-spark-opt-out-choice-in-wa-from-my-health-record-ng-b88951068z>

<sup>21</sup> Australian Digital Health Agency, 2018, Provider awareness and opinion tracking results, Sydney.

<sup>22</sup> Dr Ines Rio (2018), Opinion, *Why I wish my father had a My Health Record*, The Sydney Morning Herald, 24 July 2018, <https://www.smh.com.au/national/why-i-wish-my-father-had-a-my-health-record-20180724-p4ztbi.html>

<sup>23</sup> Newcastle Herald, (2018) *My Health Record opt out period begins, but residents are urged to embrace program*, 16 July 2018, <https://www.theherald.com.au/story/5529237/my-health-record-opt-out-period/>

<sup>24</sup> Professor Fiona Stanley, (2018) Letters, The West Australian, *Health register is a universal win*, 28 July 2018, <https://www.pressreader.com/australia/the-west-australian/20180728/282076277668852>

<sup>25</sup> Department of Health and Ageing. Review of the Personally Controlled Electronic Health Record. Canberra; 2013. <https://delimeter.com.au/wp-content/uploads/2014/05/FINAL-Review-of-PCEHR-December-2013.pdf>

<sup>26</sup> Department of Health and Ageing. Review of the Personally Controlled Electronic Health Record. Canberra; 2013

<sup>27</sup> Siggins Miller (2006). Evaluation of the participation trials for the My Health Record <https://www.health.gov.au/internet/main/publishing.nsf/content/A892B3781E14E1B3CA25810C000BF7C6/%24File/Evaluation-of-the-My-Health-Record-Participation-Trials-Report.pdf>

<sup>28</sup> Australian Digital Health Agency, Board Advisory Committees, <https://www.digitalhealth.gov.au/about-the-agency/board-advisory-committees>

<sup>29</sup> National Health Service, NHS Digital, Summary Care Record, <https://digital.nhs.uk/services/summary-care-records-scr>

<sup>30</sup> Federal Ministry, Labour, Social Affairs, Health and Consumer Protection, ELGA – Electronic Health Records, [https://www.bmgf.gv.at/home/EN/Health\\_care\\_services/ELGA/](https://www.bmgf.gv.at/home/EN/Health_care_services/ELGA/)

<sup>31</sup> E-estonia, Healthcare, 'e-health records', <https://e-estonia.com/solutions/healthcare/e-health-record/>



Australian Government

Australian Digital Health Agency

## Attachment A – Clinician perspectives

Clinician	Perspective of how My Health Record
George Dervenis BHLthSc, MPhysioPrac, APAM from Melbourne VIC	“My Health Record is a way to ensure that the care I am providing is standardised, is patient-centric and is communicated effectively to the patient’s treating team. As a physiotherapist, I appreciate the potential for improved health outcomes a central digital record may provide at both individual and population levels”
Dr Rowan Ellis  Resident Medical Officer Perth WA  MBBS, BSc (Human Bio, Sci Coms), GradCertMed(CritCare), CHIA	“In my current role assessing patients prior to their surgery I have the complex task of collating information on medical history, medications, allergies, specialist reviews, and pathology and radiology reports which have been completed outside of my hospital. It can take hours or days until this information is faxed to my clinic once a request is sent, despite the need to make urgent decisions on fitness of patients to undergo anaesthesia. I have discussed this situation with many of my patients and they have all be supportive of the benefits that the My Health Record will bring. The benefits in my daily work will be immediate.”
Dr Ralph Hanson  Sydney NSW  BSc (Med) MBBCH, MPH    Paediatrician	<p>“Consider the inconvenience recently shared with me by a patient. They developed palpitations and a sense of panic while staying on a remote property. She was seen promptly in a local general practice and after a thorough assessment and investigations was advised to see a Cardiologist. She was reassured that her record would be uploaded to MHR and available to doctors in Sydney.</p> <p>On returning to Sydney she had recurrent symptoms and was reviewed by her regular GP. Despite having signed up to MHR, no information had been uploaded. The fact that she had a sibling who died from a similar event was lost. As the initial practice could not be reached, her tests were repeated, delaying care and contributing further to her stress. The initial assessment and investigations were not shared even at the time of seeing a specialist a few days later. This is simply not good enough!”</p>
Dr Christine Pascott  Perth WA  MBBS, FRACGP, GAICD, AFACHSM    General Practitioner	<p>“We have over 3000 new patients accessing our medical practice each year. Collecting a medical history from each of these individuals is a time consuming endeavour.</p> <p>As uploading of health information grows and the MHR becomes increasingly comprehensive, the task of creating and maintaining an accurate record will become easier for our practice doctors.</p> <p>The high patient turnover in our practice, makes the MHR a very important tool for continuity of quality, comprehensive clinical care”</p>
Dr Chandrashan Perera  Melbourne VIC	“MyHR is an opportunity to improve Australian healthcare delivery substantially by combining disparate sources of information into one

MMed (OphthSc), MBBS, BMedSci (Hons) Trainee Ophthalmology Registrar	place, allowing clinicians to have a more complete picture of the patient they are treating”
Mr Jamie Marshall Inverell NSW M.Psych (Clinical), B.A. (Hons.) (Psych.), Grad. Dip. Soc. Sci., MAPS  Clinical Psychologist	“As a mental health clinician in a rural private practice, there are many potential benefits that My Health Record could provide to people suffering from mental illness, particularly those with complex presentations and living in rural areas. For too long, the Australian health system has been fragmented and disjointed, resulting in unsatisfactory patient outcomes and wasted time for clinicians. I have already seen how My Health Record can improve the health outcomes of individuals suffering from mental illness through providers having improved access to information leading to better co-ordinated care for patients.”
A/Prof. Charlotte Hespe Sydney NSW MBBS (Hons), DCH (Lon), FRACGP, FAICD, GCUT (UNDA)  General Practitioner Academic	<p>“MHR is the ideal way for Australians to have a communication portal that enables true patient centred care through access by the relevant health care providers to key elements of health care: Demographic details, Allergies, Medication history and relevant medical history, as well as summaries of health care incidents and investigation reports.</p> <p>Currently as a GP I do not have a way of ensuring my patients can have these key elements communicated between healthcare providers and this has lead to medication and management errors as well as unnecessary invasive and expensive investigations.</p> <p>I have already seen that by assisting my elderly and multimorbidity patients enrol and upload an accurate health summary into MHR we can improve healthcare delivery through the availability of these summaries. For instance, clarification of prescribed medication that prevented a potentially unsafe investigation and procedure and communication of allergies that prevented potential anaphylaxis.”</p>
Dr Caroline Yates Brisbane QLD MBChB, FRACGP  General Practitioner	“As a GP practicing in very low socio-economic areas (including remote indigenous communities), and with vulnerable patients, I see risk, inequality, real harm and inefficiency in health care because I cannot access all the relevant information required to properly care for my patients. Even for engaged, compliant and health literate patients, the complexity and multi-morbidity experienced by Australians means that keeping track of all investigations, specialist opinions, and medications is extremely difficult. The current system of faxing information back and forth, or phoning up to request downloads is outdated, unsecure and inefficient. A secure online storage facility for this information is long overdue in the current digital age.”
Dr Shane Jackson Hobart TAS BPharm, PhD  Pharmacist National President, Pharmaceutical Society of Australia	<p>“The My Health Record system will transform the role of the pharmacist in the healthcare system. It will transform how health professionals use medicines. It will make the health system safer for a patient because their treating health professionals will have relevant information available at their fingertips. It will reduce duplication, it will save lives.</p> <p>From a pharmacist’s point of view, access to verifiable clinical information will allow the pharmacist to ensure that a medicine is safe and appropriate for the patient. No second guessing, no more wondering about why a doctor has made a specific decision. The pharmacist will have a much more complete (not totally complete) picture of a patient’s medication and their relevant medical conditions. This will allow a pharmacist to be the medication safety goalkeeper, preventing medication errors and prescribing issues because they are now fully equipped with the necessary information to intervene.</p>

	<p>Think, reduced opioids, think improved prescribing of antibiotics, think increased access to medicines such as those used for migraines and urinary tract infections because a pharmacist can access relevant information to make the right decisions and provide that information to the My Health Record so that others understand too.</p> <p>This will help patients and will help pharmacists be more responsible and accountable for medication safety.”</p>
<p>Dr John Aloizos AM MBBS FRACGP FAICD Brisbane QLD General Practitioner</p>	<p>“My patient’s My Health Record allows me to instantly access to the most recent prescribed and dispensed medicine information in the Medicines Information View. While I’m having a conversation with my patient, I’m updating any changes in my own electronic medical record system. I feel more confident knowing that the medicines information is more current and accurate and reliably allows the clinical decision support software to review the updated medicines list and minimise the risk of allergic reaction or adverse drug reactions on any of the changes and for any new medicines that I prescribe when making clinical management decisions.”</p> <p>“It’s heartening to know that my patients have secure access to their summary health information, including medicines information via the My Health Record national consumer portal and instant access via their My Health Record mobile phone App, allowing them to view their clinical information and also share this information with their other healthcare providers when they choose to.”</p> <p>“I’ve been discussing the My Health Record with my patients since July 2012, especially focusing on those who suffer from chronic illness and older aged patients, and along with my practice staff have been assisting them to Opt-in. The response from my patients has been overwhelmingly positive during that time. We welcomed the decision to Opt-out at my practice, because it now means that all my patients can have a My Health Record, unless they choose to Opt-out.”</p>



Australian Government

Australian Digital Health Agency

## Attachment B – The role of the My Health Record in national healthcare strategic plans

Strategy	Visions and Objectives	Role of My Health Record
<b>The National Strategic Framework for Chronic Conditions</b>	<p>All Australians live healthier lives through effective prevention and management of chronic conditions.</p> <p>The Vision is supported by the following three Objectives:</p> <ol style="list-style-type: none"> <li>1. Focus on prevention for a healthier Australia.</li> <li>2. Provide efficient, effective and appropriate care to support people with chronic conditions to optimise quality of life.</li> <li>3. Target priority populations.</li> </ol>	<ul style="list-style-type: none"> <li>• A universal electronic health record (My Health Record) is used to securely share health information between health care providers.</li> <li>• A universal health record (such as the My Health Record) has the potential to facilitate secure, real-time sharing of health information. A continuing and stronger focus is required to facilitate broader sharing of information between all health workforce sectors.</li> </ul>
<b>The Roadmap for National Mental Health Reform 2012–2022</b>	<p>A society that values and promotes the importance of good mental health and wellbeing, maximises opportunities to prevent and reduce the impact of mental health issues and mental illness and supports people with mental health issues and mental illness, their families and carers to live full and rewarding lives</p>	<ul style="list-style-type: none"> <li>• Improve access to quality electronic information and enable people to access effective online mental health information services, treatments, and web-based and video-link consultations.</li> </ul>
<b>Australian Medical Research and Innovation Strategy 2016-2021</b>	<p>A health system fully informed by quality health and medical research.</p> <ul style="list-style-type: none"> <li>• Create health and economic benefits from research discoveries and innovations</li> <li>• Embed research evidence in healthcare policy and in practice improvement</li> <li>• Drive collaboration and innovation across the research pipeline and healthcare system</li> <li>• Strengthen transdisciplinary research collaboration</li> </ul>	<ul style="list-style-type: none"> <li>• The collection, curation, linkage and application of health data across the health system must be nurtured, and where possible integrated with the digital health agenda via My Health Record.</li> <li>• Providing access to health data facilitates evidence-based care and drives efficient use of resources. This applies to clinician-captured data, surveillance information, clinical quality registries, biobanks, and the wealth of data related to the new 'omics' technologies. These datasets and the means to analyse them will be the basis of the future health system architecture and will drive new advances in healthcare.</li> </ul>

Strategy	Visions and Objectives	Role of My Health Record
	<ul style="list-style-type: none"> <li>• Provide better access to research infrastructure</li> <li>• Maximise opportunities for research translation by engaging with consumers</li> <li>• Position the research sector and health system to tackle future challenges</li> <li>• Facilitate the commercialisation of great Australian research</li> <li>• Demonstrate the value and impact of research investment</li> </ul>	
<b>National Aboriginal And Torres Strait Islander Health Plan 2013–2023</b>	<p>The Australian health system is free of racism and inequality and all Aboriginal and Torres Strait Islander people have access to health services that are effective, high quality, appropriate and affordable.</p> <p>Together with strategies to address social inequalities and determinants of health, this provides the necessary platform to realise health equality by 2031.</p> <p>Targeted, evidence-based action that will contribute to achieving equality of health status and life expectancy between Aboriginal and Torres Strait Islander people and non-Indigenous Australians by 2031</p>	<ul style="list-style-type: none"> <li>• Improve access to health information including eHealth, recognising that for many Aboriginal and Torres Strait Islander people, language or lack of transport may be an additional barrier to accessing health services.</li> <li>• Enhance health system performance in areas of access, coordination, integration, responsiveness and the use of technology where these encourage increased use by Aboriginal and Torres Strait Islander people, including those with a disability and those incarcerated</li> </ul>
<b>National Primary Health Care Strategic Framework</b>	<p>The Framework will prioritise action toward the following four strategic outcomes, which have been identified as requiring concerted focus:</p> <ul style="list-style-type: none"> <li>• Build a consumer-focused integrated primary health care system;</li> <li>• Improve access and reduce inequity;</li> <li>• Increase the focus on health promotion and prevention, screening and early intervention; and</li> <li>• Improve quality, safety, performance and accountability.</li> </ul>	<ul style="list-style-type: none"> <li>• Action 2.5 Maximise the opportunities of eHealth, including the Personally Controlled Electronic Health Record (PCEHR) and Secure Messaging initiatives.</li> <li>• 3.3 Undertake research and evaluation to identify the best use of new technologies and enable increasing use of home based monitoring, treatment and support.</li> </ul>
<b>National Diabetes Strategy 2016-2020</b>	<p>Strengthen all sectors in developing, implementing and evaluating an integrated and coordinated approach for reducing the social, human and economic impact of diabetes in Australia</p> <ol style="list-style-type: none"> <li>1. Prevent people developing type 2 diabetes</li> <li>2. Promote awareness and earlier detection of type 1 and type 2 diabetes</li> </ol>	<ul style="list-style-type: none"> <li>• Promote the uptake and meaningful use of the My Health Record by consumers and health care providers</li> <li>• Encourage sharing of care and transition plans between health professionals and individuals through the use of the My Health Record</li> </ul>



Strategy	Visions and Objectives	Role of My Health Record
	<p>3. Reduce the occurrence of diabetes-related complications and improve quality of life among people with diabetes</p> <p>4. Reduce the impact of pre-existing and gestational diabetes in pregnancy</p> <p>5. Reduce the impact of diabetes among Aboriginal and Torres Strait Islander peoples</p> <p>6. Reduce the impact of diabetes among other priority groups</p> <p>7. Strengthen prevention and care through research, evidence and data</p>	<ul style="list-style-type: none"> <li>Facilitate and improve the connectivity of key data systems between different providers of health care, including through increased participation with the My Health Record</li> <li>Explore the role of the My Health Record in clinical workflows so as to better manage complex conditions and medication among the individual's health care providers</li> </ul>
<b>National Strategic Framework for Rural and Remote Health</b>	<p>People in rural and remote Australia are as healthy as other Australians.</p> <p>Rural and remote communities will have:</p> <ol style="list-style-type: none"> <li>Improved access to appropriate and comprehensive health care</li> <li>Effective, appropriate and sustainable health care service delivery</li> <li>An appropriate, skilled and well-supported health workforce</li> <li>Collaborative health service planning and policy development</li> <li>Strong leadership, governance, transparency and accountability.</li> </ol>	<ul style="list-style-type: none"> <li>Support the adoption of information and communications technology for e-Health, telehealth and electronic health record applications.</li> <li>Promote adherence to national e-Health standards.</li> <li>Work with consumers and health professionals to promote understanding of how the health system works, including emerging technologies such as e-Health.</li> </ul>



## Attachment C – Consumer perspectives

My Health Record user	How they are using the My Health Record
Julie Aboriginal Health and Community Services	<p>“We have 790 transient clients so if, for example, a client from the Northern Territory visits us, it is not easy to get hold of their doctor. Having a My Health Record means our GP can access their important information quickly”.</p> <ul style="list-style-type: none"> <li>Aboriginal Health and Community Services provide services to thousands of clients, many with multiple chronic conditions.</li> </ul>
Melissa Caring for her husband	<p>“Where is my health before My Health Record? You know, a specialist has got some piece of it, the hospital has got another piece of it, my GP’s got some of it, if I see another GP they’ve got another piece. It needs to be all put into one place, and it is”.</p> <ul style="list-style-type: none"> <li>Melissa maintains her family of four’s health records while caring for her husband who lost in eye sight during an accident. Melissa says maintaining her family’s health records can be daunting because not everything is provided in hard copy so you have to come home and handwrite everything.</li> <li>My Health Record provides Melissa peace of mind, knowing if anything happens there’s a digital record in place. It also means Melissa doesn’t need to rely on her memory to manage her family’s health – which she knows from experience can be difficult.</li> </ul>
Bill Managing prostate cancer	<p>“You’ve got this life preserver of My Health Record that can tell any practitioner anywhere in Australia your health history – and it’s just so important.”</p> <ul style="list-style-type: none"> <li>Bill’s battle with prostate cancer involved a range of health professionals. Bill says when his prostate specific antigen (PSA) levels rise, his doctor prescribes a Positron Emission tomography (PET) scan. Bill is pleased the results of the PET scan are available to any practitioner he sees so they know exactly where he is at in his health journey.</li> </ul>
Khadija Healthcare consumer with sensitive health issues who wants her privacy protected	<p>“I just knew my health records could allow me to determine who saw my record and who didn’t see my record”</p> <ul style="list-style-type: none"> <li>Khadija came to Australia in 2001 with her family as a refugee. She experienced Female Genital Mutilation (FGM) as a young child, which means her pregnancy was high risk, and she experiences a lot of pain.</li> <li>She also has numerous health concerns, including thalassaemia and anaemia, and is constantly accessing medical services as a result. Khadija says the way the health system manages health records is clunky, particularly when records have to be sent from one provider to another. She feels that as a result, there’s a lot of people who intrude on her privacy in numerous ways, especially regarding her treatment around FGM and domestic violence. She didn’t want everyone to see that.</li> <li>Khadija says that registering for a My Health Record was a no-brainer because it helps control who sees her record and protects her privacy</li> </ul>

My Health Record user	How they are using the My Health Record
Zoe Young person managing her health records after serious injury	<p>"Moving out of home and interstate meant I wasn't visiting my family GP anymore. But even though I was in a different location, all of my health records were available in one place."</p> <ul style="list-style-type: none"> <li>A recent injury put a pause on Zoe's life saving career. A hip labral tear stopped her being able to do most of her regular physical activity. As a result, she had to have keyhole surgery to repair the damage and get her movement back to full strength.</li> <li>The My Health Record was helpful in terms of managing the information that came from the different doctors and health professionals that Zoe visited, especially after moving out of the family and relocating from NSW to Queensland.</li> <li>The My Health Record allowed all her scans and records to be in the one place, so she could see what she had been up to and her health practitioners could see those records as well.</li> </ul>
Dot Older person who want her health information to travel wherever they go	<p>"John and I are on a number of medications so having a My Health Record means that wherever we are, the need for those medications, the amount, and the dosage are clearly and safely recorded and can accompany us anywhere."</p> <ul style="list-style-type: none"> <li>Dot's health history has been complicated. She and her husband John travel a lot and use My Health Record so that she always has access to her important medical information, like medications.</li> </ul>
Donna Primary carer for her daughter, Marnie	<p>"It really provides me with a level of security and confidence, probably reduces that anxiety of if I wasn't here someone will know about Marnie's story, that Marnie will be managed appropriately."</p> <ul style="list-style-type: none"> <li>When Marnie suffered a massive haemorrhage at 16, she need ongoing full time care. Her mother, Donna, became her primary carer</li> <li>Donna says the My Health Record gives Marnie a voice because over time they'll be able to see what's occurred with her hospitalisations, what's happened with her blood tests, which can be used to managed Marnie's next steps of treatment</li> </ul>
Terry (name changed) Healthcare consumer with chronic health conditions	<p>"I would recommend My Health Record to all people, young and old, because you never know when you need it."</p> <ul style="list-style-type: none"> <li>Terry from Townsville has developed a myriad of chronic health conditions and uses My Health Record to keep track of his health.</li> <li>A plant operator and miner all his life, he developed a number of serious health conditions, including a heart disease, diabetes, kidney failure, arthritis, gout, sleep apnoea, reflux, emphysema. Terry takes 14 medications at breakfast, and 10 at tea time, and the information is readily available in the My Health Record.</li> <li>With Terry's many conditions, it was an issue for provider to get information quickly that was accurate, and My Health Record is an excellent way for all of Terry's providers, including his cardiologist, urologist, endocrinologist (who don't communicate with each other) to keep track of Terry's treatment.</li> </ul>
Rob Torres Strait Islander with multiple health conditions	<p>"Australia is a big place. Especially when you're looking at Indigenous people, and where Indigenous people live. For them to travel, might be the Torres Strait or out in Normanton or somewhere like that, most of them travel for health reasons. In that sense where they don't have to carry, their record goes with them."</p> <ul style="list-style-type: none"> <li>Rob has a number of health conditions which takes a lot of time explaining to a new health provider. Rob and his wife Sandra use My Health Record when they travel, to give their healthcare providers a convenient snapshot of their health.</li> </ul>
Nick Recovering from a serious heart attack	<p>"It helped me having a digital copy of everything instead of having to go to my GP or my cardiologist with a binder full of everything – my blood tests; my discharge summaries."</p> <ul style="list-style-type: none"> <li>Nick suffered a heart attack after a football game, and has used My Health Record to manage his care as he recovers.</li> </ul>

My Health Record user	How they are using the My Health Record
Juliana Mother of a child with chronic illness	<p>“As a mother of a child with a chronic illness, it gives me great comfort and assurance to know that wherever he goes, his complex medical history including an allergy will be available at the point of care with MHR to ensure that he gets the right care. It can be there when I’m not.”</p> <p>“As a health practitioner, I have seen first-hand the power of having clinical history available at the point of care to ensure safe and quality care in a hospital setting. MHR extends this beyond the physical boundaries to improve equity of access to appropriate care when it is most needed for every individual .”</p>

Additional views from consumers are in [video case studies](#) on the Agency website.



## Attachment D – My Health Record: Misconceptions and Frequently Asked Questions

### Misconceptions

#### ***Every aspect of a consumer's health records will be in the My Health Record and can be seen by everyone***

The My Health Record does not include a patient's whole history. On the day the record is created, it will be empty. On a patient's first interaction with the health system (or when a consumer logs on to the system themselves) two years of MBS and PBS data will flow into the record, unless the consumer has set a control to prevent this from occurring.

Only certain types of documents then start flowing into the record – medicine prescription and dispense records, hospital discharge summaries, pathology test results and diagnostic imaging reports, specialist letters, event summaries and a curated shared health summary by a consumer's GP. Medicare data such as the Australian Immunisation Register, Organ Donor Register and MBS/PBS data also go into the record.

A consumer can enter their own information such as personal health notes, over the counter medications, advance care directives, and emergency contact details.

Consumers can remove any records and set access codes to the entire record or to particular documents. No one can see those records without the PIN supplied by the consumer, unless there is an emergency – in which case a healthcare provider can 'break the glass'. Every instance of this type of access is investigated by the Agency.

#### ***Any healthcare provider can browse the My Health Record and view anyone's information***

The My Health Record cannot be "browsed" by a healthcare provider; ie a full list of records is not available for a healthcare provider to just peruse through an internet connection.

Rather, healthcare providers need to have individual and organisational identifiers installed on their systems – obtained following a rigorous process administered by the Department of Human Services. Their software that connects to the My Health Record must have passed conformance tests administered by independent NATA accredited test labs and the Agency, and loaded with encryption security keys to access the record.

Even then, providers can only access patients who are already registered in their clinical information system, and need a number of pieces of information about the patient in their system to be able to access a patient's record, such as full name, date of birth, medicare card number and address. They must be providing healthcare services to the patient to be authorised to access the system.

#### **A consumer will not know who is accessing their record**

The My Health Record provides more visibility to a consumer about who is accessing their record than any other medical system in the country, and possibly the world.

Every access to every health record is logged in an audit trail and immediately visible to the consumer. A consumer can elect to get a text message or email when a new healthcare provider accesses the record or when certain things happen to the record such as a new shared health summary being uploaded, or when someone 'breaks the glass' to access their record. This all occurs in real time.

A consumer can view the audit log through MyGov (either on a computer or mobile device) and see every healthcare provider that has accessed their record, when, and what they accessed. They can contact the call centre to raise any concerns, and the Agency will follow this up with the healthcare provider, and liaise with the Privacy Commissioner if required.

Anyone who accesses the My Health Record who is not authorised faces fines and a potential custodial sentence. These penalties significantly exceed penalties in the Privacy Act for unauthorised access to other types of health records outside the My Health Record.

### **Young people over 14 cannot prevent their parents from seeing their health information**

Parent's access to the My Health Record for their children changes as the child grows older. Of the six million My Health Records, more than one third (2.05 million) are for a person under 18. Of those, the vast majority, 1.8 million, have a parent as an Authorised Representative. Being Authorised Representative means that the parent can take control of and manage the child's My Health Record on the child's behalf. If a parent does not take control of the child's record, the record will still be available to health professionals who are providing care to the child.

Until a person under 18 takes control of their own Record a person with parental responsibility (usually a parent) can be an Authorised Representative. The role of Authorised Representative until a young person 18 is specified in the MHR Act and the MHR Rule. Unless a young person takes control of their My Health Record, their parents may have access to their clinical information (except MBS and PBS data).

Agency policy specifies that if the child is 14 or over and under 18, the child can take control of their record online or via the call centre. This is in line with processes followed by other government agencies such as Medicare.

When this occurs, the parents (Authorised Representatives) and any Nominated Representatives are automatically removed at this point. The child can provide access to their parents (or others) if they choose by appointing them as Nominated Representatives. If the child has not taken control, the Medicare Repository does not provide information on MBS and PBS to the MHR in line with broader Department of Human Services policy relating to parental access. Therefore, this information is not available to either parents or clinicians.

Agency policy specifies that for children under 14, the child is able to take control of their own record by establishing that they are a mature minor. This is done by contacting the call centre and providing a letter from a health professional or a court. The child can still choose to provide access to a parent (or others) by appointing them as a Nominated Representative.

The Agency has met with and briefed a number of organisations including the National Children's Commissioner, the Australian Association for Adolescent Health and Orygen Youth Health. Specific material have been developed to communicate on the MHR to young people and their parents which have been reviewed by young people through Orygen Youth Health and will continue to provide information and support young people to take control of their record when they are ready.

## **Frequently Asked Questions**

### **What are the extended dates for the opt-out period?**

On 10 August 2018, Health Minister Greg Hunt announced that the opt-out period would be extended until 15 November 2018.

This is to ensure all Australians have an opportunity to make an informed decision as the government strengthens the 2012 My Health Record legislation.

### **What does the Minister for Health's announcement about legislation changes mean for me?**

The Minister has announced that the government will change the My Health Record legislation to:

1. Require by law that a court order is required to access a person's My Health Record – in practice this was already the policy of the System Operator, and no record has ever been released in the past and no government agencies other than the System Operator have access to the system.
2. Permit the complete deletion of a person's My Health Record if they choose to cancel it – under the current law, the Agency cancels a record and archives the record for 30 years after the death of the record holder. Under this practice only the System Operator can access this archive and it is not visible to any healthcare providers or the individual.

## **Access to My Health Record**

### **What is Section 98 of the My Health Records Act 2012?**

Section 98 of the My Health Records Act 2012 is a very common statutory provision in the vast majority of Commonwealth and State and Territory legislation.

It allows the Australian Digital Health Agency, who is the System Operator of the My Health Record, to delegate some of its functions and or powers for the efficient, secure and effective administration of the My Health Record system.

This delegation is used for administrative and procedural matters - for example, to enable the Department of Health to provide education on the My Health Record system. This does not and cannot provide access to individuals' personal records or any other health information in My Health Record.

The Agency's number one priority is to protect the privacy and security of health information in the My Health Record system.

The Federal Minister for Health has made it clear that the legislation will be amended to reflect the current Australian Digital Health Agency operating policy which is that My Health Record information cannot be released to police or government agencies (such as the Australian Tax Office or Border Force) without a court order.

### **Can anyone access my health information?**

The My Health Record System was designed at its core to have the highest level of security and privacy to protect your health information.

Only registered healthcare providers involved in your care and who are registered with the My Health Record System Operator are allowed by law to access to My Health Records.

My Health Record data cannot be accessed by insurance companies and patients' data cannot be sold.



## **How will I know my record has been accessed?**

The Agency Monitors your health record around the clock to protect your records security and privacy.

There are steps you can also take to apply additional privacy and security controls to your record.

You can also see which healthcare provider organisation has accessed your record in the access log in your My Health Record. This allows you to have complete visibility of who is accessing your record.

You, as the record owner, can set up automatic notifications to receive an email or SMS alert when a new healthcare organisation accesses your My Health Record for the first time, or in an emergency

You can also apply a record access code to your entire My Health Record so that only those healthcare providers with that code are able to access your record.

## **Who can access my private health information?**

There are thousands of registered organisations who can access My Health Record. However, only healthcare provider organisations involved in your care, who are registered with the My Health Record System Operator are allowed by law to access your My Health Record.

This may include healthcare providers such as GPs, pharmacies, pathology labs, hospitals, specialists, and allied health professionals. Organisations require compliant software to access the My Health Record system.

You can allow others, such as a partner, child, parent or carer to access your Record by making them an authorised representative, or a nominated representative.

No government departments can directly access the My Health Record system.

The Australian Digital Health Agency will only consider a request from a law enforcement agency to access a My Health Record where there is a requirement by law, such as a court order or other enforceable legal instrument.

Every time your My Health Record is accessed, it is recorded in an audit log which you can view by logging into your My Health Record. The System Operator cyber security team constantly monitors system access. There are strict penalties for unlawful access.

If you have concerns about who has accessed your My Health Record, contact us immediately on 1800 723 471.

## **How do healthcare providers get access to the My Health Record system?**

For a healthcare provider, such as a doctor or pharmacist to gain access to the My Health Record system they must:

- be a registered health care professional with a national registration board, such as AHPRA
- have registered with the My Health Record System Operator
- Work for an organisation which is a registered with the My Health Record System Operator
- Use conformant software containing an authenticated digital certificate.

To upload any information to your My Health Record, your healthcare provider must use compliant clinical software.

If the healthcare provider downloads a patient's information to their clinical information system, this is subject to the Australian privacy, security and jurisdictional laws that currently govern the healthcare system in Australia.

Will everyone in my doctor's office know my private health information, including the medical receptionist?

Administration staff within your doctor's office must be authorised by the medical practice to access the My Health Record system for the purposes of providing healthcare to you.

In the current health system, paper and digital records about you may be held in various health locations. There is no way you can currently track who has viewed, photocopied, faxed, shared or filed your medical information.

The addition of My Health Record to your doctor's practice and process of care does not change the privacy and confidentiality obligations that practice staff are already subject to under Australian law.

## Past and sensitive clinical information

### **Will my past medical history be added into my record?**

Your previous medical history such as older tests and medical reports will not be available within your new My Health Record.

Medicare data can be added to your record.

This includes:

- Medicare and Pharmaceutical Benefits Scheme (PBS) information stored by the Department of Human Services
- Medicare and Repatriation Schedule of Pharmaceutical Benefits (RPBS) information stored by the Department of Veterans' Affairs
- organ donation decisions
- immunisations that are included in the Australian Immunisation Register

You can ask your doctor to add a shared health summary to summarise your medical history, or add your own personal health summary.

You can log into your record at any time to change your settings, see who has accessed your record, hide documents, remove Medicare or PBS data or add emergency contacts and any allergies you may have.

### **Will my doctor be able to find out about past or current medical issues that I consider sensitive?**

It's your choice what information is in your My Health Record, and who you share it with.

You can advise your doctor not to upload any information about sensitive clinical conditions. You can also choose to hide, or restrict access to clinical documents by logging into your My Health Record and setting privacy controls.

Your medical history, such as older tests and scan reports, will not be automatically uploaded to your My Health Record.

I've seen a new tick box on pathology reports that says "Do not send to My Health Record". Are records uploaded by default and you must withdraw consent? Who sets whether it is opt out or opt in to each upload?

The 'Do not send to My Health Record' tick box on the new pathology form is an opportunity for the patient and their GP to discuss if they would like their results uploaded to their record (if they have one) before the patient takes the test.

For people who don't want a report added to their My Health Record, providers can tick the 'do not send to My Health Record' box on the request form. People can also instruct their doctor or the pathology or diagnostic imaging service not to upload the report.

In addition, individuals can set document access controls within their My Health Record, and remove pathology and diagnostic imaging reports from their record.

In some circumstances, certain pathology reports may not appear in an individual's My Health Record, even if they have not withdrawn consent for upload, in accordance with legislation. For example, reports may not be uploaded on a person's AIDS or HIV status if there are disclosure restrictions set by state or territory legislation.

### **Are genetic / DNA reports uploaded to My Health Record?**

There are a number of genetic tests used by clinicians every day to provide health care.

Conditions like cystic fibrosis, types of anaemia and iron storage disorders have been diagnosed in general practice with genetic tests for many years.

Doctors also depend on genetic testing to routinely screen for neural tube and other issues in early pregnancy as a standard practice for all Australian women as part of routine antenatal care. Genetic screening plays an important role in the early diagnosis and screening for cancers like breast cancer and ovarian cancer, and plays a vital role in tailoring specific treatments for people with many different types of cancers.'

These tests are vital in ensuring the best and most appropriate treatment by your healthcare team.

My Health Record cannot store Genomic or Genetic Data, but it can support the uploading of reports so that your authorised healthcare providers and you can view them.

In an emergency, clinicians knowing about your healthcare conditions is important information that could be lifesaving.

My Health Record is a secure patient-controlled electronic health summary record. Only health care providers involved in your care can access the system.

Like any other pathology test, you can ask your doctor at any time for a specific test not to be uploaded into your My Health Record.

You can also remove a document from your record or apply a Limited Document Access Code restricting access to that document for only those who you give the code to.

Ultimately, the choice is yours if you want a genetic test report uploaded into your My Health Record. It's best to speak with your doctor to decide what's best for your individual care needs.

## **Cybersecurity**

### **Can My Health Record easily be hacked?**

The My Health Record system has the highest level of security and meets the strictest cyber security standards. It has robust multi-tiered security controls to protect the system from malicious attack.

The system has been built and tested to Australian Government standards to protect the confidentiality, integrity, and availability of information within an individual's My Health Record.

The Australian Digital Health Agency actively monitors and respond to threats and risks within the cyber security environment, and have a program of continuous improvement using the internationally recognised management framework, Information Technology Infrastructure Library (ITIL).

The System is monitored around the clock by the Australian Digital Health Agency Cyber Security Centre and has been tested by the Defence Departments Australian Signals Directorate.

If a person deliberately accessed an individual's My Health Record without authorisation, criminal penalties may apply. These may include up to two years in jail and up to \$126,000 in fines.

### **Will my records be available on the open internet? (for example, via Google search)**

My Health Record cannot be accessed on the open internet. Healthcare provider organisations must be authorised to connect to the system and use conformant clinical information software.

### **Who can access a My Health Record?**

#### **Will the police, Centrelink and ATO have access to my medical records?**

As System Operator of the My Health Record system the Agency takes its role as custodian of Australian's health information seriously. Protecting the integrity of the My Health Record system and maintaining public confidence and trust in the system is paramount.

We consider any formal request on a case by case basis. However, our operating policy is to release information only where we are legally compelled to do so, including in the instance of receiving a court order.

The Agency would not permit access to a My Health Record in a scenario where a request to access the My Health Record system was for protecting public revenue.

#### **Can my employers access a My Health Record?**

Employers cannot access a My Health Record and would need to apply to the Agency for such access.

The 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 Agency does not consider that an employment check is healthcare and therefore use of the My Health Record would not be permitted.

#### **Can insurance companies and other third parties access my data? Can it be sold on?**

My Health Record data cannot be accessed by insurance companies and your data cannot be sold.

The use of My Health Record data solely for commercial and non-health related purposes is not permitted.

Some secondary uses of My Health Record system data may be possible for research and public health purposes from 2020. Learn more about this [here](#).

You can choose not to have your data used for secondary use purposes by selecting the 'withdraw participation' function in your record.

### **Children and My Health Record**

#### **How do parents currently decide whether to register newborns for a My Health Record?**

Currently, parents can choose whether to register a child for My Health Record as part of the Newborn Child Declaration form in the Parent Pack. This allows parents to manage and view their child's record on their behalf. Find out more.

## **How can parents decide whether they want their children to have a My Health Record after the opt-out period?**

After the opt-out period, parents of newborn children can opt out of My Health Record for their child as part of their Medicare registration.

## **How do I opt out my child?**

If you have parental responsibility for children under the age of 18, and they are listed on your Medicare card, you can opt out of My Health Record on their behalf online.

## **Why do I already have a My Health Record? I don't remember signing up for one**

5.9 million Australians currently have a My Health Record. Most people have registered themselves or their children for a My Health Record in one of the following ways:

- via a myGov account
- Medicare enrolment form (for a newborn)
- at a Medicare Service Centre
- by calling the Help line on 1800 723 471
- you were a resident in a participation trial area in 2016.

If you already have a My Health Record, and decide you don't want one anymore, you can cancel it at any time.

## **Cancel a My Health Record**

### **If I get a My Health Record and then cancel it, will my record be viewable?**

When you cancel a record, your data can no longer be accessed by your healthcare providers, or by you.

For medico-legal reasons, the System Operator is required to retain cancelled records for a period of time as outlined in the My Health Records Act 2012.

### **I have cancelled my record, but now I want it deleted. Can you do this?**

The government's decision will need to be enacted into legislation. The System Operator will implement this decision once legislated. Until this time, if you have a My Health Record you can cancel it. If you do not have a My Health Record, and don't want one, you can opt out.

Under the current law, the Agency cancels a record and archives the record for 30 years after the death of the record holder. Under this practice only the System Operator can access this archive and it is not visible to any health care providers or the individual.

## **Opting out of My Health Record**

### **Why do I need to provide my personal details to opt out? What do you do with my information?**

Basic demographic information including (but not limited to) your name, address, date of birth and Medicare details is needed to ensure the system can identify you, and record your choice to opt out of

having a My Health Record created for you at the end of the opt-out period. This information is not used for any other purpose.

**Will I lose access to Medicare services if I opt out?**

If you are eligible to get Medicare services, you will continue to get these services, even if you decide to opt out.

**Who is the System Operator of the My Health Record system?**

The Australian Digital Health Agency (the Agency) is the System Operator of the My Health Record system.