



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



## **Interoperability and Connected Healthcare in Australia Early Engagement Paper**

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## 1 Introduction

The Australian Digital Health Agency has a broad brief to advance digital health in Australia. In particular, its legislation mandates that the Agency:

- (e) develop, monitor and manage specifications and standards to maximise effective interoperability of public and private sector digital health systems; and
- (f) develop and implement compliance approaches in relation to the adoption of agreed specifications and standards relating to digital health"[1].

This early engagement paper deals with how the Agency may best perform this wider function of creating a more connected healthcare system through improved interoperability. The previous body, the National E-Health Transition Authority produced a framework for interoperability in 2007. However much has changed since 2007. There have been a number of new technologies developed and an overall strengthening of core internet based cybersecurity. To inform this consultation and co-design process, Ernst & Young (EY) were commissioned to assess the current state of interoperability, including lessons learned and key enablers from other industries and countries.

As noted by the Australian Nursing and Midwifery Federation in their submission to *Australia's National Digital Health Strategy – Safe Seamless and Secure*[2]:

*...interoperability between systems is an ongoing issue. Individuals' health records are placed on varying health facilities systems across the country, and in many instances these are still hard copy or scanned copy records. A consumer does not have ready access to these records, let alone any choice in how their own records are managed and who can access them*[3].

Interoperability holds the potential to bring patients' records together from a range of systems, give consumers and providers greater visibility, enable consumers to have control and transparency over who sees their records and enable research and innovation to assist Australia's dedicated clinical professionals in their invaluable work. There are well documented safety risks to patients associated with the lack of availability of information, especially at the transition of care[4].

As with the National Digital Health Strategy, the intention is to develop a direction that has broad acceptance in terms of its goals and timeframes from a diverse group of stakeholders in industry, community, healthcare providers, jurisdictional bodies and the Commonwealth. The National Health Interoperability Roadmap should serve as the national roadmap, not just the Agency's.

Ultimately, interoperability will only be advanced in Australia if there is an agreement amongst government and non-government stakeholders to make a co-ordinated set of improvements in their systems that make information available and consume that information to support care delivery and consumer self-management. In order to gain this agreement, it is essential these co-ordinated improvements have a broad base of stakeholder support and endorsement.

## 2 Context

Australia's health system is a complex mixture of public and private sector service providers, funded through equally complex, largely activity based, models that include Commonwealth, jurisdictional, insurance company and consumer contributions. Even with this complexity, our health system consistently ranks as one of the best in the world[5].

Healthcare business models range from sole provider practices to large corporate or jurisdictional services. This diverse community of practice is served by national and international software companies providing information systems which are usually not cloud-based. This means that the bulk of the information about patients is secured behind local firewalls and only accessible to people within the health service where the information was collected. However, patients rarely received end to end care within a single practice, with

referrals required for specialist services, including diagnostics and most procedures. This information environment creates the possibility of information gaps and clinical risks, especially when patients transition from one setting to another.

Australia's healthcare system, like many around the world, is grappling with a number of issues around the rights and responsibilities associated with data access and use. While sharing information that can assist in providing the best possible care for a patient is reasonably well accepted, there are concerns about the use of consumer information outside of this context[6], including the use of data in research without explicit individual consent. In addition, there are concerns surrounding the use of data to compare outcomes across service provision environments[7].

The emergence of Artificial Intelligence approaches to decision support in acute and non-acute settings have the potential to assist in the earlier diagnosis[8] and improved management[9-11] of chronic and acute conditions. However, these approaches require access to vast amounts of data, for not just the individual patient involved, but also for the broader cohort.

These circumstances create challenges for the community at large, but especially for the healthcare workforce of the future. There is little doubt that clinicians' work will continue to involve, probably increasingly, the use of digital technology. It is unclear at this time what impact this will have on the requirements for vocational and continuing professional training.

### 3 Connected Care Vision

In developing the National Digital Health Strategy more than 3000 people attended the 103 forums, workshops, webcasts and town hall meetings held across Australia. Over 1000 submissions and survey responses were analysed and four key themes emerged, forming the foundation of the Strategy:

- Support me in making the right healthcare choices, and provide me with options.
- Help all the people who care for me to understand me, and together, provide safe and personalised care.
- Create an environment where my healthcare providers and I can use and benefit from innovative technologies.
- Preserve my trust in the healthcare system and protect my rights.

Digital technology is transforming and positively disrupting many industries. In almost every part of our lives, whether it's banking, travel or maintaining social or business connections, technology has changed the way we do things. There are some common themes in these changes that will ultimately cross over into the healthcare sector, namely:

- Information follows the person.
- Each person, whether they are a provider or consumer of services, sees the relevant information in a single view, in a way that works best for them.
- Business or social interactions are an activity, not a place.
- Professionals are supported by decision support systems that assist them to provide services, based on the individual's information and needs.

#### Consultation Questions

Do you support these themes as broadly framing an interoperability vision for healthcare in Australia?

How might this vision be articulated?

Digital health applications are now widely used in all parts of health, including hospitals, general practices, pathology, radiology, specialists, and aged care. Currently, most digital health applications serve a single health service setting, such as the workflow needs within a hospital or General Practice. The information collected about the patient in one health service setting is mostly not made available to others involved in a patient's care. In the same way that healthcare services are 'siloes', so are the digital applications that they use.

The inability to exchange personal health information routinely creates significant barriers to improving healthcare in Australia. For example:

- When a person attends a hospital Emergency Department, clinicians do not have information about a person's allergies or current medications, creating significant clinical risk.
- Diagnostic test results done outside of the hospital are not available when a person is admitted to hospital, creating inefficiencies through repeat tests.
- Referrals between medical specialists, hospitals, general practitioner and allied health professionals are still mostly paper based, often with minimal clinical information available.
- Patients receive radiology information on outdated technology, often still a physical x-ray film and images are not easy for specialists or other clinicians to access electronically.
- Many Australians do not have the information they need to take control of their own healthcare or manage their child's health, such as patterns of diagnostic test results.
- The complexity of healthcare makes it difficult to navigate, and Australians want more information to make better choices about their healthcare.
- Digital innovations, such as smart phone technology for self-monitoring, are not integrated into the clinician's care of the person.
- Expanded use of telehealth for consultations is constrained by lack of digital access to a patient's health records.

The impact of this falls most heavily on the socially disadvantaged who have chronic health conditions that need multiple health services over an extended time.

There is a risk that connected care will bypass those who need it most, creating digital exclusion. A digitally inclusive health strategy should make it easy for all to access the connected healthcare world, and not be dependent on high levels of digital literacy, or even on the affordability of being 'on line'.

Connected healthcare, and the innovation that comes with it, can benefit all involved in healthcare:

- For consumers, it will be easier to access healthcare, create a better experience ('I don't have to tell my story from the start all over'), and enable the person to manage their own health and make better choices.
- For health service providers, it will help to reduce the risk of adverse events and improve the efficiency of delivering healthcare.
- For governments and funders, it will slow the growth in costs by reducing demand for expensive hospital services arising from better care co-ordination for high users of healthcare.
- For industry, connected healthcare can create an environment for innovation. The smart phone ecosystem has opened the possibility for innovators to create new ways of relating and transacting. This is described in the National Digital Health Strategy, which envisions "a thriving digital health industry delivering world-class innovation".

The prerequisite for achieving this connected care vision is to create an interoperable ecosystem between the various, currently siloes, information systems used in healthcare.

## 4 What is Interoperability?

The National Digital Health Strategy[2] defines interoperability as:

*At its simplest, it is the ability to move information easily between people, organisations and systems. It is imperative that when information is shared between people and systems, its meaning is preserved from one context to another so that information is interpreted in the same way.*

Fundamentally, there are two ways in which health information systems can exchange information:

- In a human readable format, where the receiving clinician uses their training and experience to interpret what was meant. This is essentially what healthcare practitioners have always done with letters, reports and so on flowing between providers without a rigorously standardised terminology; and
- In a machine readable format, where it is essential that all software systems must use exactly the same language (standard terminologies) to communicate concepts like diagnoses, pathology tests, procedures, appointments etc. This is a more complex undertaking, but is an essential foundation for future innovation.

Both these approaches are dependent on being able to accurately and uniquely identify the patient and having a mechanism to exchange the information, whether that is point to point or via a data warehouse.

While the Agency is working with industry groups to increase the adoption of standardised terminology, we need to ensure that we incrementally solve real problems, affecting real people. Dr Doug Fridsma, President and CEO of the American Medical Informatics Association has noted:

*...interoperability isn't a utopian place. It's about incremental added functionality. Going from a paper record to a PDF to something that is more structured — each one of those provides additional interoperability and the ability to both exchange information and use the information that's been exchanged.[12]*

## 5 What Can We Learn From Other Industries And Countries?

There is much to learn from the experience of other industries and other countries' health systems.

Examples of successful interoperability in other industries include the financial services sector, the aviation sector, and the smartphone ecosystem. An examination of these industries by Ernst and Young shows common themes:

- The need for clear regulatory and legislative frameworks. For example, in the financial services sector, clear rules and protocols are set and governed by the Reserve Bank of Australia's Payments System Board and by the Australian Prudential Regulatory Authority.
- Reliance on standards bodies. The telecommunications industry has a single global mobile standard: the Global System for Mobile Communications (GSM). In the smartphone environment, the rules for developers to participate in the ecosystem are set by the operating system controllers.
- Clear leadership. For example, in the aviation industry, all airlines rely on the International Civil Aviation Organization (ICAO), and the European Organisation for Civil Aviation Electronics.
- Collaboration and self-regulation. For example, the Australian Payments Network (AusPayNet) is a membership-based industry association that acts as a self-regulatory body.

This points to the need to resolve the issue of 'who sets and enforces the rules' for Australian healthcare interoperability, and the balance between government and self-regulation.

Other countries have taken various approaches to health interoperability. A summary of these countries that are most relevant to Australia's healthcare system may be found at <http://files-au.clickdimensions.com/digitalhealthgovau-a5xdx/files/internationalcomparisons.pdf>

There are recurring themes across different health systems that point to issues that need to be resolved in the Australian healthcare context to promote interoperability, and in doing this, connected healthcare:

- Most countries have a government body with some responsibility for standards and interoperability, although this varies from ‘mandating’ to ‘facilitating’. Some countries complement this with a degree of self-regulation.
- There are varying approaches to how data is exchanged, some with centralised data repositories and others with distributed models where patient data is stored in the original collection point and extracted when required.
- Most countries have a system of unique patient identifiers, with some extending this to both health and social system (with clear benefits of an integrated social approach to healthcare).
- Most countries draw on international terminology standards, rather than creating their own.
- Various ‘levers’ have been used to promote adoption, ranging from mandating standards, to stipulations in funding agreements, to providing resource materials (toolkits, implementation guides).

## 6 What makes interoperability work in a complex health system?

The following seven enablers are the foundations of interoperability.

Enabler	Relevance to interoperability
 <p>Identity management</p>	<p>Uniquely identifying health consumers, health and care providers and health organisations in the healthcare ecosystem.</p> <p><i>‘I am who I say I am’.</i></p>
 <p>Authentication and authorisation</p>	<p>Ensuring appropriate levels of access to a patient’s health information.</p> <p><i>‘As a clinician, I can get access to the information I need to provide care’.</i></p> <p><i>‘As a consumer, I have access to my information and have control over who can access it’.</i></p>
 <p>Integrated electronic health record</p>	<p>Allows health consumers, health and care providers and other participants to access health information, with the consumer at the centre.</p> <p><i>‘My health information is available to clinicians involved in my care’.</i></p>
 <p>Unified health directory services</p>	<p>Provide the technology for health consumers and health and care provider to find health services quickly.</p> <p><i>‘I can easily find the health and care providers I need to communicate with electronically’</i></p>
 <p>Information exchange</p>	<p>Developing clinical informatics specifications to facilitate information exchange in alignment with relevant data quality and clinical safety requirements.</p> <p><i>‘My clinical software communicates with other systems to bring me what I need’.</i></p>
 <p>National standards</p>	<p>Promoting the definition and adoption of consistent standards to facilitate information exchange and provide conformance and compliance mechanisms.</p> <p><i>‘Minimum standards are accessible and easy to understand and implement’.</i></p>
 <p>Security</p>	<p>Common standards, understanding and adhering to required policies to protect the privacy and integrity of information.</p> <p><i>‘I can rest assured that my information is secure’.</i></p>

## 7 What shifts to current Australian paradigms do we need to consider?

Comparing international and other industry approaches to interoperability exposes a number of opportunities for Australia. While individual technologies or implementation approaches will need to be co-designed at a later time, this analysis suggests a number of possible paradigm shifts that may be appropriate in the Australian context. These are described below.

### **Moving away from an exclusive reliance on a document paradigm**

Currently, My Health Record receives information in one of a range of document types that are available for different purposes[13]. There are some advantages to this model: It reflects the traditional practice of healthcare to communicate in documents and does not require a high degree of common terminology. Specialists in Australia, for instance, are familiar with reading referral letters from General Practitioners who have trained and practiced globally, and have differences in terminology.

While documents will continue to play an important role in healthcare communication, some data may be better captured in an atomic form. Atomic data captures information in discrete packets that represent something about a person or service. Frequently, this is numerical data, representing a blood test result, a height, weight, heart rate or blood pressure

### **Strengthening the use of identifiers for patients, providers and services.**

Most Australians have an Individual Healthcare Identifier[14]. However, not all regular care users in Australia have an Individual Healthcare Identifier (IHI). There are also variations in how IHI's are looked-up, stored and used in different care provision settings.

It is just as important that we are able to identify providers of care in order to make information on patients available to them. Current provider identification systems, including NASH certificates, are cumbersome and there are ways in which these can be streamlined without compromising security.

### **Develop new collaborative models for the governance and approval of standards and specifications**

The implementation of co-ordinated improvements will require a multitude of decisions as to "how". Without agreement on how information will be made available, requested and transmitted, widespread implementation is impossible.

The standards and specifications that define all of this must be developed collaboratively with industry and with a strong focus on suitability for use in the clinical setting.

The process itself for achieving this must be developed in partnership with stakeholders.

### **Extending the role of My Health Record to include acting as a trust broker to facilitate access to information or resources that are held on other systems.**

Currently, My Health Record acts primarily as a repository for information. Clinical information is uploaded into My Health Record by some people and downloaded by others. This limits the type and amount of information that My Health Record is able to facilitate access to. In the age of wearable devices and widespread home monitoring, there may be value in enabling consumers to use My Health Record to link information from disparate sources. Similarly, My Health Record could provide capacity to link a radiology report to the associated images (stored elsewhere) enabling clinicians to have faster access to diagnostic images.

## 8 Data rights and responsibilities in Australia

Globally, the issues associated with access and custodianship of information are being redefined in ways that reflect the changing nature of a consumer's relationship with information about themselves or those that they care for.

The European Union has introduced the General Data Protection Regulation[15], which comes into force on 25 May 2018. These regulations includes provisions for:

### *Right to Access*

*Part of the expanded rights of data subjects outlined by the GDPR is the right for data subjects to obtain from the data controller confirmation as to whether or not personal data concerning them is being processed, where and for what purpose. Further, the controller shall provide a copy of the personal data, free of charge, in an electronic format. This change is a dramatic shift to data transparency and empowerment of data subjects.*

### *and Data Portability*

*GDPR introduces data portability - the right for a data subject to receive the personal data concerning them, which they have previously provided in a 'commonly use and machine readable format' and have the right to transmit that data to another controller.*

A similar approach is envisaged in the United States with the US Office of the National Coordinator for Health Information Technology defining interoperability as[16]:

*the ability of a system to exchange electronic health information with and use electronic health information from other systems without special effort on the part of the user.*

This reference to 'without special effort' draws upon the growing body of agreed, open-source, Application Programming Interfaces that allow consumer facing applications (like Apple's new Health Application) to draw information from a range of clinical systems using a standardised approach with the consumer's consent. Essentially, Government and Industry have collaborated to define a set of interfaces, increasing over time, by which systems share information that becomes the de facto standard of what is reasonable as opposed to being 'special effort'.

In Australia, the *Privacy Act 1988* governs how personal health information is managed by government and the private health sector, with additional legislative requirements applying in states and territories for state based health providers. The Privacy Act and the Australian Privacy Principles it contains, give the consumer the right to access to their own health information, with entities who hold that information obliged to provide it in the manner requested by the individual unless one of a number of lawful exceptions applies. The principles provide that an entity may charge the consumer the reasonable costs of providing this information in the manner requested.

The Australian Government Productivity Commission examined the issues associated with data availability and use, reporting in 2017[17]. This report made a number of observations regarding the potential to improve outcomes and the effectiveness of the health system more generally. Importantly, the report makes the following recommendation:

*Marginal changes to existing structures and legislation will not suffice. Recommended reforms are aimed at moving from a system based on risk aversion and avoidance, to one based on transparency and confidence in data processes, treating data as an asset and not a threat. Significant change is needed for Australia's open government agenda and the rights of consumers to data to catch up with achievements in competing economies.*

- *At the centre of recommended reforms is a new Data Sharing and Release Act, and a National Data Custodian to guide and monitor new access and use arrangements, including proactively managing risks and broader ethical considerations around data use.*
- *A new Comprehensive Right for consumers would give individuals and small/medium businesses opportunities for active use of their own data and represent fundamental reform to Australia's competition policy in a digital world. This right would create for consumers:*
  - *powers comparable to those in the Privacy Act to view, request edits or corrections, and be advised of the trade to third parties of consumer information held on them*
  - *a new right to have a machine-readable copy of their consumer data provided either to them or directly to a nominated third party, such as a new service provider*

These proposed reforms, and the emergence of consumer-facing applications nationally and internationally, demonstrate a growing expectation in the community that a consumer's data both can and will be made usefully available.

**Consultation Question:**

Do you think there will be a strong demand for access to information electronically in consumer facing applications?

How can Australian industry meet that demand?

What level of safeguards are required?

Where people have particular needs, e.g. the vision impaired, how do we ensure that their access to data in an accessible form is considered at the outset?

## 9 What are the priorities for agreement and action?

*...interoperability is defined by the thing you want to do. That's why the practical approach to measuring and defining interoperability is to say, what do you want to do, and given that, what's the functionality you need to make it happen?[12]*

While the highest degree of research and innovation is made possible through atomic longitudinal data sets, there are a number of privacy and ethical issues that would need to be worked through before these could be developed, if that is the endpoint that Australia chooses to pursue. In any case, the required infrastructure to support these would not be available for some time to come.

There are opportunities to make healthcare safer and more efficient using infrastructure that is already available, or able to be developed in a reasonable time frame.

The Agency would like to achieve industry, jurisdictional, consumer and clinician endorsement for a number of initiatives that address current issues. These initiatives would:

- Support consumers in the management of their health.
- Support consumers and referring providers in navigating referral pathways.
- Facilitate communication with or between providers.
- Bring information from a range of sources into a single view.
- Improve the completeness and trust of health records.
- Improve clinical workflow and the accessibility of information at the point of care.
- Assist patient in booking appointments, including factors that impact patients like out-of-pocket costs and waiting times.
- Be feasible within a reasonable timeframe and cost.

- Be aligned with evidence-based care provision and clearly deliver benefits to the community.
- Improve patient safety and satisfaction.

**Consultation Question:**

In your view, what are the key opportunities that we, as a society and nation, should pursue?

## 10 Sensitivities, costs and other issues associated with implementation

Implementation of a more interoperable health system is not a simple matter. Consultations that have been undertaken for both the National Digital Health Strategy[18] and the Development of a Framework for the Secondary Use of My Health Record System Data in Australia[6] have revealed concerns over the security and privacy of information and the purposes for which it might be used.

Implementation will also come at a cost. While the Agency currently provides tools and support that reduces costs for vendors, the costs associated with bringing legacy systems into line with contemporary interoperability standards will be substantial. Ideally, the directions determined in Australia would support the Australian software industry to invest in innovations that compete on a global scale.

Implementation of an interoperable healthcare environment may also have future impacts on the models and workflow of care delivery by bringing a whole of patient, whole of life approach to people's health information. Especially in general practice, but also in other areas of practice, our funding models are largely episode and activity based.

It is also questionable whether current funding models support and require high quality data capture and sharing across all sectors of healthcare.

**Consultation Questions:**

What barriers might be associated with the opportunities you identified earlier?

Are there any key sensitivities that you can foresee in having a conversation with the broader community around these opportunities and interoperability more broadly?

Who do you think these sensitivities can be addressed?

What broader changes might support a more interoperable and connected healthcare system?

## 11 Equity Considerations

*The right to health is the right to the enjoyment of the highest attainable standard of physical and mental health[19].*

There is a clear gradient of burden of disease among Australia's socioeconomic strata, with the most disadvantaged socioeconomic quintile experiencing a 50% higher burden of disease than the least disadvantaged quintile. There is also a disproportionate burden of disease among Aboriginal and Torres Strait Islander people [20].

As health becomes more digitally oriented, there are opportunities to improve access to services and information among isolated people and assist people with lower health literacy make healthier choices.

There is also the risk that adoption of digital technology might be strongest among the well-educated and affluent, and that those who lack access to, or skills to use, the required technology will be left behind.

Whether digital health improves or increases the differences in outcomes will largely depend on the degree to which implementations actively account for equity concerns in the design of programs and the extent to which these consider the range of contexts that Australians live in.

These concerns were clearly articulated during submissions for the National Digital Health Strategy with the Rural Doctors Association of Australia noting:

*Digital health is increasingly being promoted as a cost-effective way to redress the inequities of access to health care and significantly poorer health outcomes that exist. However, a 'digital divide' exists between city and country. A lack of enabling human, financial and technological resources compromises the ability of rural and remote doctors and other health professionals, and their patients, to use digital health technologies[21].*

The Consumers Health Forum of Australia also stated:

*Of particular concern to the Agency should be the 'digital divide'. Digital health consumers should not be treated as one homogeneous group in the services offered or the way they are offered. Australians who live in regional and remote Australia have considerably less access to the internet than their city counterparts, which directly impacts on how they can access health care. .... Consumers' ages also impact on their use of digital health resources. While there are exceptions to this, younger Australians are more likely to be early adopters and more technologically savvy than their older counterparts. Older Australians experience greater barriers to using digital health resources as part of their care. The notion of digital inclusion and how to promote digital inclusion is very important. According to work undertaken by the Centre for Social Impact in 2016, Australia's digital inclusion index is on the rise but it is still quite low with some groups very digitally excluded[22].*

## 12 Next Steps

The Agency is developing a National Interoperability Roadmap. As with the National Digital Health Strategy, the intention is to develop a direction that has broad acceptance in terms of its goals and timeframes from a diverse group of stakeholders.

Ultimately, interoperability will only be advanced in Australia if there is an agreement amongst government and non-government stakeholders to make a co-ordinated set of improvements in their systems that make information available and consume that information to support care delivery.

In order to gain this agreement, it is essential that these co-ordinated improvements have a broad base of stakeholder support and endorsement. To achieve this, the Agency will facilitate a national conversation that will aim to identify the nation's interoperability goals, principles and priorities.

### Consultation Questions:

Do you have any recommendations as to how a broader consultation can be undertaken?

Would your organisation will willing to assist us in facilitating some future consultation?

How can we ensure that we address equity considerations in the consultation process?

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