

**Australian Government
Department of Prime Minister and Cabinet**

**Submission to the Consultation into the New
Australian Government Data Sharing and Release
Legislation**

3 August 2018

OUR VISION

A healthy Australia, supported by the best possible healthcare system.

OUR MISSION

To conduct research, educate and influence the healthcare system to achieve better health outcomes, improved patient and provider experience, greater equity and sustainability.

OUR GUIDING PRINCIPLES

Healthcare in Australia should be:

Effective
Accessible
Equitable
Sustainable
Outcomes-focused.

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CONTENTS

- Contents 1**
- Introduction 2**
 - Background..... 2
- 1. Key principles of the data sharing and release legislation 3**
- 2. Scope of the data sharing and release legislation 4**
 - My Health Record – Particular Considerations 5
- 3. Streamlining data sharing and release 6**
 - The Purpose Test..... 6
 - Other Considerations 7
- 4. Roles and responsibilities within the system 8**
- 5. National Data Commissioner 8**
- 6. Conclusion..... 9**



INTRODUCTION

The Australian Healthcare and Hospitals Association (AHHA) is pleased to provide this submission to the consultation into the new Australian Government Data Sharing and Release legislation.

AHHA is Australia's national peak body for public hospitals and health care providers. Our membership includes state health departments, Local Hospital Networks and public hospitals, community health services, Primary Health Networks and primary healthcare providers, aged care providers, universities, individual health professionals and academics. As such, we are uniquely placed to be an independent, national voice for universal high-quality healthcare to benefit the whole community.

AHHA acknowledge the intention for the value of public data in Australia to be maximised and recognises the importance of data governance reforms to support healthcare that is accessible, equitable, sustainable, effective and outcomes focussed.

AHHA also recognise that it is imperative for the public to retain trust and confidence in the way government data is used, shared and released. For data related to healthcare, this is particularly the case given the sensitivity of the material it contains.

It should also be recognised that a breach of data sharing and release standards in one area of government activity can have a negative spillover effect to other areas of government activity and data release. This negative externality is particularly relevant to the public trust and confidence in the My Health Record system given the perpetual individual right to delete or mask the information contained within their record.

BACKGROUND

An issues paper for consultation¹ was released by the Australian Government in July 2018 to outline an approach to the Data Sharing and Release Bill, aiming to balance sharing data held by government with appropriate risk management. This consultation paper was in response to the Productivity Commission report on data availability and use.² The consultation paper explores:

1. Key principles to guide the development of legislation
2. The scope of the proposed Data Sharing and Release legislation
3. A process for data sharing and release
4. Roles and responsibilities within the system; including those of a
5. National Data Commissioner

¹ New Australian Government Data Sharing and Release Legislation – Issues Paper for Consultation. At: <https://www.pmc.gov.au/resource-centre/public-data/issues-paper-data-sharing-release-legislation>.

² Productivity Commission 2017. *Data Availability and Use, Inquiry Report*.



1. KEY PRINCIPLES OF THE DATA SHARING AND RELEASE LEGISLATION

AHHA supports in principle the aims of the Data Sharing and Release Bill identified in the consultation paper, being to:

- a. Safeguard data sharing and release in a consistent and appropriate way
- b. Enhance the integrity of the data system
- c. Build trust in the use of public data
- d. Establish institutional arrangements
- e. Promote better sharing of public sector data

In terms of health data, AHHA recognises that many Australians are generally willing to share their de-identified data on the condition that it will be used for improving the health and wellbeing of the Australian public. Australians also have clear expectations that the privacy of their health information will be respected and their rights protected.

AHHA submits that the issue of identifiability will be central to the integrity of the data sharing and release system since protecting an individual privacy is fundamental to minimising risk associated with the sharing and release of data held by the Government. The capacity for an individual to consent to the release of their full or partial data, and the ongoing reassessment of that consent, must be respected.

Dynamic consent research³ indicates that individuals being fully informed about the uses data are put is a crucial aspect of achieving trust and acceptance in such disclosure. AHHA submits that building trust and ongoing public confidence in the use of public data will require a comprehensive strategy to increase public awareness and understanding of:

- The value of data sharing and release
- How data is shared and released
- How individual privacy is protected
- Recourse(s) available to breaches of privacy

AHHA notes that as data collected by the Government changes over time, there should be ongoing consideration of the public's understanding of data sharing and release to ensure current and continued informed consent.

³ Kaye, J et al 2015, Dynamic consent: a patient interface for twenty-first century research networks, European Journal of Human Genetics: EJHG [Eur J Hum Genet], Vol. 23 (2), pp. 141-6.



2. SCOPE OF THE DATA SHARING AND RELEASE LEGISLATION

The proposed scope of entities and data covered by the Data Sharing and Release Bill is limited to Commonwealth entities and Commonwealth companies. AHHA submits that the broader public policy intent should be for a nationally consistent approach across all entities and tiers of government in order to:

- Meet community expectations
- Consistently and appropriately safeguard the data of all Australians
- Leverage the opportunities and minimise the barriers for data linking and sharing across jurisdictions and entities

AHHA supports a progressive move towards establishing a nationally-consistent framework, such that data held by cooperating jurisdictions have the ability to become integrated and accessible. Within the health sector, non-government providers of government subsidised healthcare should also be required under the terms of the funding arrangements to provide specified de-identified patient and service data for public reporting.^{4,5} AHHA also supports extending the national framework to include clinical data registries, where this is possible.⁶

As a first step, AHHA submits that the proposed legislation on the sharing and release of government data should not be delayed while broader cross jurisdictional agreements are established. However, reaching agreements on the release of government data held by other jurisdictions must be proactively pursued in order to fully realise the public benefit of providing access to data collected on government programs. This is particularly the case in the health sector where there is considerable fragmentation in the collection of data among a number of custodians within the health system.

AHHA notes that a number of jurisdictions across Australia already have open data access policies. This demonstrates the broad recognition of both the valuable public resource that government data represents and the potential public benefits from innovative use of this data. AHHA is also aware of innovative developments to consolidate local health data from both government and non-government sources.⁷

⁴ Refer to *Health people, healthy systems - Strategies for outcomes-focused and value-based healthcare: a blueprint for a post-2020 national health agreement*, Australian Healthcare and Hospitals Association, 2017. At: <http://ahha.asn.au/Blueprint>.

⁵ Duckett S, Swerissen H and Moran G. 2017. Building better foundations for primary care. Grattan Institute. At: <https://grattan.edu.au/report/building-better-foundations/>.

⁶ The potential for disease registry integration and data sharing to support value-based healthcare is discussed in The Economist Intelligence Unit, 2016, Value-based healthcare: A global assessment. At: <http://vbhcglobalassessment.eiu.com/value-based-healthcare-a-global-assessment/> (Australian results [here](#)). National arrangements for clinical quality registries has been considered by the Australian Commission on Safety and Quality in Health Care. At <https://www.safetyandquality.gov.au/our-work/information-strategy/clinical-quality-registries/>.

⁷ For example, POLAR (Population level analysis and reporting) consolidates data from general practice, community health, hospitals, ambulance, government, ABS and other population-based health areas. A key element in being able to successfully collect data from private general practices is the capacity to report



MY HEALTH RECORD – PARTICULAR CONSIDERATIONS

While the secondary use of My Health Record system data is subject to a separate legislative and governance framework⁸, it is imperative that public confidence and trust be maintained with any framework that enables the release of government data.

This is particularly salient with regards to My Health Record data as individuals have a perpetual right to delete or mask from view any or all parts of their health record. This contrasts to most other governments datasets that are fully controlled by government.

The integrity of this vital healthcare sector resource must not be compromised either directly or indirectly through poor management of government data releases including in non-health related domains. If the public's confidence in the ability of government to appropriately manage data sharing and release is diminished, this could have a significant impact on future participation by individuals in the My Health Record system.

A pertinent example of the potential to negatively impact upon public trust is the inappropriate release of government data by the Department of Health in 2016 when claims data was released on a 10 per cent sample of people who received Medicare benefits since 1984 and pharmaceutical benefits since 2003. While the data release was intended to inform medical research and policy development, researchers at the University of Melbourne were able to demonstrate that it was possible to reverse the encryption used to de-identify the data.

It has also recently been reported that the Australian Digital Health Agency has supported the development of software that will enable genetic information to be recorded on an individual's My Health Record.^{9,10,11} While there are potentially valuable gains for individuals from the ready availability of their genetic information, it is also perhaps among the most highly sensitive of personal information. This further underlies the necessity of public trust in any framework that enables government data to be shared and released.

actionable insights back to participating practices that reinforces the value of contributing the (de-identified) patient data. POLAR was initially developed by Inner East Melbourne Medicare Local. Further details on POLAR can be found at <https://outcomehealth.org.au/polar.aspx>.

⁸ Section 15(ma) of the My Health Record Act 2012 enables the System Operator (the Australian Digital Health Authority), "to prepare and provide de-identified data for research or public health purposes". The Framework to Guide the Secondary Use of My Health Record System Data then identifies AIHW as the Data Custodian for the purposes of the Framework. This Framework is available at <http://www.health.gov.au/internet/main/publishing.nsf/Content/eHealth-framework>.

⁹ Esther Han, My Health Record can store genomic information but critics say it's not ready, Sydney Morning Herald, viewed 6 August 2018. At: <https://www.smh.com.au/healthcare/my-health-record-can-store-genomic-data-but-critics-say-it-s-not-ready-20180801-p4zuxz.html>.

¹⁰ Alana Mitchelson, My Health Record prompts concerns over storage of DNA data, The New Daily, viewed 6 August 2018, At: <https://thenewdaily.com.au/money/consumer/2018/08/06/my-health-record-dna-privacy/>.

¹¹ Wendy Bonython, The troubling implications of My Health Record's genetic info plans, Sydney Morning Herald, viewed 8 August 2018. At: <https://www.smh.com.au/national/the-troubling-implications-of-my-health-record-s-genetic-info-plans-20180807-p4zvz1.html>.



3. STREAMLINING DATA SHARING AND RELEASE

AHHA supports the development of a flexible and modern framework for sharing and releasing government data. The framework must:

- Work alongside existing ethics and grant review practices
- Be adaptable and robust to an evolving environment of healthcare provision, data policy and ethics practices, including incorporating limitations and allowances for new sources of data or data gained through emerging technologies
- Include the maintenance of a publicly available register of data released under this legislation

AHHA agrees with statement by the Minister Assisting the Prime Minister for Digital Transformation The Hon Michael Keenan MP that, “Australia’s data is an important national resource which, when used correctly, can greatly assist consumers, researchers, government agencies and industry to better understand the world we live in and to make sound investment decisions based on evidence”.¹²

This strategic national resource contains latent value to improve patient care and population health, realise economic gains and better achieve government policy objectives. In order to realise the value of data sharing and release, there needs to be a strong and clear cultural shift to encompass sharing and use with the broader community, not just within government.

In addition to informing broader issues of public interest beyond immediate government activities, government data sharing should reflect transparency and accountability to the Australian public about what informs the development of government policies and programs.

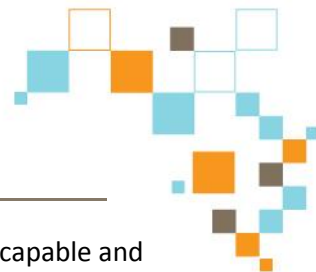
THE PURPOSE TEST

The purpose test outlined in the consultation issues paper is inappropriately narrow and inward looking to the government.

There are four criteria for the sharing and release of Australian Government data, with the first three focussing on existing government policies and operations. The fourth criterion is constrained to “research and development” and an undefined requirement for “clear and direct public benefits”.

AHHA submits that these four criteria do not adequately capture the intended scope of uses to which government data could be appropriately applied. For example, a publicly beneficial contestability of policy development and advice could require data to be used beyond the scope of current government policies and operations. “Research and development” could also be narrowly interpreted to exclude broader analysis of data that has the potential to establish insights and meaningful patterns such as in population health or in the examination of service utilisation patterns.

¹² The Hon Michael Keenan MP, *Government response to Productivity Commission Inquiry into data availability and use*, media release 1 May 2018.



As noted by the Productivity Commission, “Access to data more broadly would enable capable and trusted researchers to play a more active role in developing solutions to seemingly intractable problems. This can be achieved through early and routine release by governments of non-sensitive datasets, and the adoption of robust processes for assessing and managing risks associated with other datasets to better allow sharing.”¹³

AHHA considers that there must be appropriate limits on the sharing and release of government data. For public confidence and trust in a framework that allows government data to be shared and released, there must be stringent safeguards to ensure both the privacy and confidentiality of data related to individuals. However, AHHA also recognises the need for flexibility in the construction of the purpose test which enables an appropriate range of analysis to be conducted where there is public benefit intent.

OTHER CONSIDERATIONS

The move to share and release government data should be accompanied with appropriate guidelines and background information to enable users to appropriately analyse the data. For example, there should be a data dictionary and data quality statement associated with every dataset able to be shared and released.¹⁴ Data should also be made available to users in an appropriate range of file formats.

Users of government data should also not be expected to navigate and understand the nuances of different legislation across jurisdictions in order to protect the privacy of their individual data. Appropriate guidance should therefore also be provided on any relevant legislative matters pertinent to the sharing, release and use of particular government data.

Given the important public benefits that can flow from the sharing and release of government data, users should not be charged for data requests. Initial requests for data from a given source are likely to be more resource intensive to provide than subsequent requests where only lower incremental costs are also likely to be incurred. This policy of not charging users for obtaining government data could be reviewed after a suitable period of time when it is clearer the types and frequency of data requests that are being made, and the ordinary cost to government of fulfilling these requests. A nominal rate could be considered after this initial period if excessive data requests are being submitted.

AHHA submits that a review process must be available for when an application for the sharing and release of government data is denied. This must be accompanied by a clear statement by the data custodian or Accredited Data Authority as to the reason for the denial.

¹³ Productivity Commission 2017. *Shifting the Dial: 5 Year Productivity Review*, Report No. 84, Canberra (page 166).

¹⁴ For example, refer to the data quality statement provided in Australian Institute of Health and Welfare 2017. *Health expenditure Australia 2015–16*. Health and welfare expenditure series no. 58. Cat. no. HWE 68. Canberra: AIHW. At: <https://www.aihw.gov.au/reports/health-welfare-expenditure/health-expenditure-australia-2015-16/contents/summary>.



4. ROLES AND RESPONSIBILITIES WITHIN THE SYSTEM

AHHA supports the incorporation of already existing roles and system responsibilities that are known to support risk mitigation around the sharing and release of data. This includes building on the requirements for accredited Integrating Authorities, who have strong experience in data curation, collation, linkage, de-identification, sharing and release, to provide technical expertise to data custodians, empowering them to share and release data appropriately.

AHHA supports the use of Accredited Data Authorities such as the Australian Institute of Health and Welfare and the Australian Bureau of Statistics to perform advanced data services, that ensures data sharing is released in accordance with legislative requirements and to on-share data with users in circumstances agreed with data custodians.

AHHA agrees in principle with the establishment of trusted users to assist in streamlining the sharing and release of government data. However, this category of user should not create unintended barriers to other users seeking access to government data within the stepped five-safes data release framework.

AHHA also submits that there should be a process for users of government data to provide feedback to data custodians and Accredited Data Authorities on the experience of using government data. This could include issues related to data quality, the way in which data is made available or aspects of the application process.

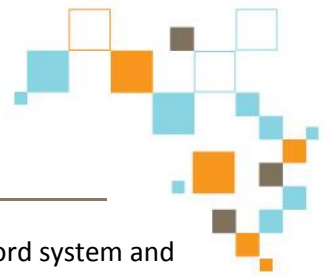
5. NATIONAL DATA COMMISSIONER

AHHA supports the establishment of a National Data Commissioner to monitor and enforce the provisions of the Data Sharing and Release Bill and any associated legislative instruments. AHHA agrees that the National Data Commissioner must consult expansively.

AHHA supports the National Data Commissioner having a role to promote best practice through proactive guidance and public reporting. This includes the National Data Commissioner encouraging the increased sharing and use of data within government. However, this role should be extended to include a proactive role in encouraging the appropriate sharing and release of data with users outside of government. Regular and timely public reporting of key performance indicators is also supported.

Due to the whole of government implications and responsibilities in consistent and appropriate data sharing and release, AHHA submits that governance structures need to facilitate the inclusion of states and territories in the activities of the National Data Commissioner and its supporting office as these jurisdictions agree to become part of an overarching framework to the sharing and release of government data.

Relevant data release legislation needs to strike a careful balance when penalising non-compliance, such that custodians are not excessively cautious in their preparedness to release government data, while also retaining appropriate standards to ensure the public's confidence in the integrity of the



data release scheme. This is particularly pertinent in the context of the My Health Record system and the perpetual right for individuals to delete or mask any or all of their individual record.

Given the particular sensitivities associated with health data and the fragmented nature of the sector in terms of data custodians and data collection practices, in addition to health sector reforms being pursued through the Council of Australian Governments, AHHA submits that the National Data Advisory Council should include representatives from the health sector.

Due to the criticality of providing assurance to the Australian public of de-identification of data shared and released, AHHA submits that the monitoring and public reporting functions of the National Data Commissioner in relation to de-identification be a key requirement to support accountability and transparency.

6. CONCLUSION

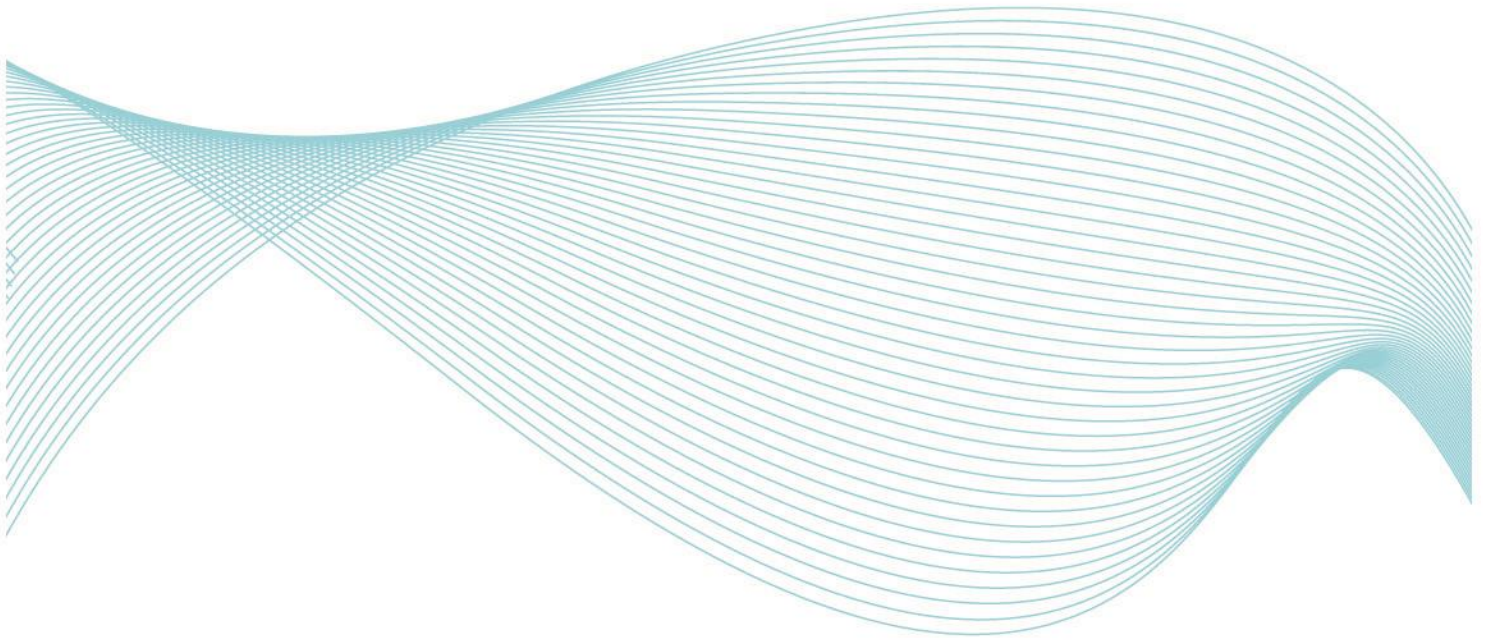
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A breach of data sharing and release standards in one area of government activity can have a negative spillover effect to other areas of government activity and public confidence in the sharing and release of any data. This negative externality is particularly relevant to the public trust and confidence in the My Health Record system given the perpetual individual right to delete or mask the information contained within their record.

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