



**Submission in response to the
Public Consultation Paper on the Development of a
Framework for Secondary Use of My Health Record Data**

17 November 2017

1 Introduction

The Australian Healthcare and Hospitals Association (AHHA) is pleased to provide this submission in response to the Public Consultation Paper on the Development of a Framework for Secondary Use of My Health Record Data.

The 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.

My Health Record, has the potential to have an unprecedented impact on the Australian health system by empowering health consumers and service providers with greater insight to the health status and usage of healthcare services than has previously been possible.

AHHA recognises that the secondary use of data kept within the My Health Record system is also a potentially significant and valuable public resource; allowing relevant information on personal health and service utilisation to be collected and analysed by researchers for the public good.

Ensuring public confidence that an individual's personal information and medical history, including diagnosis and treatment and health practitioner information remains confidential, will be critical to this process and will require transparent and effective governance by a trusted independent data custodian that controls data access and ensures that My Health Record data can only be used in appropriate ways.

AHHA submits that the Framework for Secondary Use of My Health Record data will require:

- A more comprehensive and transparent process for increasing public understanding on privacy protection and what data identifiability means than has been outlined in the consultation paper.
- Incorporating an authorised approach to the use of identified data and ongoing reassessment of consumer consent around the use of de-identified data.
- Capacity for an individual to consent to only a partial release of their data.
- Ongoing flexible data management of data so that data quality and useability is maintained and an individual's confidentiality is not compromised.
- Continued and transparent public consultation between the independent data custodian, consumers and experts in the secondary use of health data as the Framework is developed.
- The Framework to be adaptable and robust to an evolving environment of changes in healthcare provision, data policy and ethics practices.
- Obligations for secondary data users that are clearly outlined by the data custodian in respect to data use and storage.
- The release of data to researchers should adopt a risk management approach that balances the risk associated with the secondary use of My Health Record data at the level of detail requested with the potential benefits of the research proposal.

2 Secondary uses of My Health Record Data

The My Health Record is a secure online summary of health information that can be accessed by multiple healthcare providers and the patient themselves. At present, the secondary use of existing My Health Record data is not permitted and yet information held within these records is readily available, inexpensive to obtain and has boundless potential for improving Australian's health far beyond supporting an individual's clinical care.

The use of My Health Record data for secondary purposes must be with the intent to do public good. AHHA supports data use for public health purposes such as the identification of emerging health issues within communities or exporting data to health registries; developing decision support for health care providers, including the development of clinical guidelines or improving patient safety; and informing improvements in administration and service delivery, for example the identification of low value healthcare and government evaluation around the effectiveness and efficiency of health services and policy.

Publishing, linking and sharing data can create opportunities that neither government nor business can currently envisage, and recognising the variety of uses for health data will be key to facilitating wider acceptance of it use; with patient experiences of health care outcomes being a priority. The inability to recognise the potential of this data would represent a significant lost opportunity for policy development, research and the Australian community more generally, to improve our understanding of population health, individual care trajectories and potential system efficiencies.

However, data collected through the My Health Record system and used for secondary purposes has the potential to expose information about individuals. In order to protect an individual's privacy, the Framework should incorporate already existing procedures that are known to support risk mitigation around the use of data for secondary purposes including:

- Approval or accreditation of the organisation to which data is released as having met minimum data protection and appropriate use standards.
- The maintenance of a publicly available register of administrative information, or record of use, that would allow data custodians to check the identity and credentials of data users.
- Conditions on secure storage (and the need to increase capabilities for storing, sharing and analysing data).
- Prohibition of any trade or other disclosure of personal data to third parties.
- Ensuring that the data format is useable, with the capacity to correct identified errors through a responsible authority.

3 Risk to privacy and data identification

Australian's are 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. Australian's also have clear expectations that the privacy of their health information will be respected and their rights protected.

The issue of identifiability will be central to reinforcing the strength of the Framework since protecting an individual privacy is fundamental to minimising risk associated with the use of health data for secondary purposes. In order to ensure that privacy is safeguarded, the Framework will need to emphasize the public's expectations that personal information will be protected to high standards. Increasing the transparency of current data management processes will need to consider:

- The type of information that will be released from My Health Record data (for example, patient-centred data or provider-centred data; cross-sectional or longitudinal data).
- Limiting the release of data to only that which is required to investigate the research proposal.
- The Framework should work along side existing ethics and grant review practices.
- The quantity of information and potential need for standardized formats that enable comparison of aggregate data across multiple sources.
- The skills and technology available to both the data custodian and end data users so that anticipated outcomes can be achieved.
- Incorporating limitations and allowances within the Framework for new sources of data or data gained through emerging technologies.
- Public assurances that there will be appropriate recourse to breaches of privacy.

The consultation paper relies heavily on the concept that all personal data is easily rendered as de-identified. The Framework should be refocused, through further stakeholder consultation, to better explain risk minimisation and management in the context of the vital health information that can be extracted from the secondary use of My Health Record data.

The Framework should provide that data identification and re-identification be limited to the data custodian and be performed in a controlled environment. Data linkage has the potential to create great value from the information available on the My Health Record, yet it also has the potential for considerable risk for enabling re-identification of de-identified data. The Framework should provide that data linking can only be performed by a data custodian and only when absolutely necessary to investigate the proposed research questions.

The Framework also needs to more clearly state that the risk of disclosure of an individual's personal data in research outputs such as publications is low, and that for research benefits to be passed to the Australian community, knowledge obtained from my Health Record Data must be translated into changes in practice and policy. If the research should then happen to be of commercial value, then industry should in general be permitted to use it.



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