



**Australian Government**

**Department of Health**



# **Framework for Secondary Uses of My Health Record system data**

**Community Consultation Overview and Key Themes to Date**

**Webinar panel members:**

**Ms Leanne Wells, Mr Andrew Pearce and Ms Nicole Jarvis**

Consumers Health Forum Webinar

Thursday 16<sup>th</sup> November 2017 at 12.30pm (AEDST).

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# Webinar panel members – introduction

- **Ms Leanne Wells:** is the CEO of the Consumers Health Forum of Australia.
- **Mr Andrew Pearce:** is an Associate Director of HealthConsult and one of the senior team managing the project.
- **Ms Nicole Jarvis:** is the Assistant Secretary, Digital Health Branch, Health Systems Policy Division of the Australian Government Department of Health.

# Purpose of this webinar

Consultation period began on 5 October 2017 and will close at **midnight AEDT tomorrow 17 November 2017**.

This webinar provides an overview of this community consultation process and a summary of themes that have emerged to date. This feedback will be used to inform the development of a Framework for the secondary use of data in the My Health Record system.

# About the project

- HealthConsult have been engaged to develop a Framework for the secondary use of data in the My Health Record system for research, policy, planning, system use, quality improvement, and evaluation activities.
- Under the *My Health Records Act 2012*, health information in the My Health Record system may be collected, used and disclosed “for any purpose” with the consent of the healthcare recipient.
- In addition, one of the functions of the System Operator (the Australian Digital Health Agency) is “to prepare and provide de-identified data for research and public health purposes.”
- Before these provisions of the Act will be implemented, a Framework for secondary use of My Health Record system data must be established.

# Project context and objectives

- ‘Secondary use’ is defined as using the information in the My Health Record system for purposes other than the provision of direct health care to the individual person, which is the primary use.
- The use of data solely for commercial and non-health related purposes is considered out of scope.
- Secondary use of health data has the potential to enhance future health care experiences for patients by:
  - enabling the expansion of knowledge about disease and appropriate treatments;
  - strengthening the understanding about effectiveness and efficiency of service delivery;
  - supporting public health goals; and
  - assisting providers in meeting consumer needs.

# My Health Record system data

## Non-Consumer Entered Data

- ❖ Discharge Summary
- ❖ Event Summary
- ❖ Shared Health Summary
- ❖ Specialist Letter
- ❖ Referral
- ❖ Prescription Record
- ❖ Dispense Record
- ❖ Pathology Report
- ❖ Diagnostic Imaging Report
- ❖ Pharmaceutical Benefits Report (PBS)
- ❖ Medicare/DVA Benefits Report (MBS)
- ❖ Australian Childhood Immunisation Register (ACIR)
- ❖ Australian Organ Donor Register (AODR)

# My Health Record system data

## Consumer Entered Data

- ❖ Advance Care Document
- ❖ Advance Care Document Custodian
- ❖ Personal Health Note
- ❖ Personal Health Summary
- ❖ Personal Health Achievement
- ❖ Child Parent Questionnaire
- ❖ Personal Health Observations

- The My Health Record system will more than likely evolve to include more and different clinical content over time
- This will improve the potential to be an important resource for health, clinical and medical research
- This is the first dataset around the full set of health services received by a person
- It can enable time series analysis and multi-service provider analysis

# Theme - Consent to the use of data by individuals

- Dynamic consent framework preferred with options for consumer.
- Service providers need to enable consumers informed consent.
- How will re-consent be sought if the purpose changes?
- Consumers' ability to share their own data, opt out of secondary use, provide consent for use of identified data (i.e. For some purposes but not others).
- Recognition of a need for informed consent about My Health Record program expansion in 2018.
- Consumer trust in government process will be critical to ensure program success.

# Theme – Uses of data

- People need to understand what the potential of the data is in order to inform the framework effectively.
- Balancing health and commercial/public benefit use of data.
- Some reservations about allowing commercial use of data.
- People would like to see clarity in the framework on:
  - Definition of what sorts of commercial uses that would be allowed (there is interest from industry around use for innovative purposes).
  - Principles for determining the difference between commercial and non-health uses.
  - Balancing the risk of release with public good.

# Theme – Treatment of Data

- Data quality, coverage and usefulness for research.
- Timeliness of access to data.
- Data security – both of MHR generally and data released for secondary purposes.
- Data linkage
  - Is this considered to be identified or de-identified data?
  - How will the framework treat the linkage of data?
  - Start with the principles of the data linkage authorities as the model is mature and has worked well over time.
- Will different users be subject to the same access pathway e.g. researchers and Government?
- Need for Ethics committees.

# Theme – Aboriginal and Torres Strait Islander considerations

- Consent remains a sensitive issue for Aboriginal and Torres Strait Islander peoples. Will require further information on:
  - Why the data is being collected and what it is being used for?
  - How will it be reported and to whom?
  - Any secondary data uses including data linkages.
  - Where data will be stored.
- Need to consult with Aboriginal and Torres Strait Islander communities before data releases.
- Clarity on requirements around Aboriginal and Torres Strait Islander status e.g. how will Indigenous identifiers be treated if they are inconsistent in a person's record, that is, if a person who identifies as Indigenous in one forum or service but not in another.
- Social and cultural expectations around management of privacy concerns regarding data of deceased people.

# Who should you contact if you want to discuss the project?

## **Andrew Pearce**

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