Discovering the potential of Australia’s first person-centric health data set

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What is a My Health Record?

→https://youtu.be/caYPHvfYgQ
Who we are

- Independent national health and welfare data agency
- 400+ staff in Canberra and Sydney, skilled in:
  - ✔ statistical analysis
  - ✔ information development
  - ✔ communication
  - ✔ epidemiology & demography
  - ✔ data management
  - ✔ public sector administration
- Data partnerships with national and global experts and agencies
Stronger evidence, better decisions, improved health and welfare

Our purpose
- To create authoritative and accessible information and statistics that inform decisions and improve the health and welfare of all Australians
The Role of AIHW

1. Leaders in health and welfare data
2. Drivers of data improvements
3. Expert sources of valued-added analysis
4. Champions for open and accessible data and information
5. Trusted strategic partners
Required under the AIHW Act to:

- **Protect confidentiality** of data holdings
- **Report** on the state of the nation’s health and welfare every two years
Enabled under the AIHW Act to...
Data linkage at AIHW
Some examples of AIHW data collections

- Australian Spinal Cord Injury Register
- Australian Cancer Database
- Medicare Benefits Schedule (MBS) data collection
- National Drug Strategy Household Survey
- National Hospitals Databases
- Child Protection National Minimum Data Set (NMDS)
- Health Expenditure Database
- Indigenous Community Housing Data Collection
- National Aged Care Data Clearinghouse
**TODAY**

15-20 visits
A healthy pregnancy usually includes 15-20 separate encounters with health care services

40%
Death rates for remote Australians are 40% higher for coronary heart disease

$1.2B
223,000 admitted to hospital due to adverse drug event costing $1.2billion

14%
14% of pathology tests are ordered due to lack of access to patients history

**FUTURE**

Prebirth
Content shared with My Health Record means reduced risk of lost information

Adult
Digital tools make it easier to access services remotely

Older Adult
Medicines information available via My Health Record reduces safety risk

Senior
People and their clinicians will be able to see results of previous tests
High-quality data with a commonly understood meaning that can be used with confidence

Better availability and access to prescriptions and medicines information

Digitally enabled models of care that improve accessibility, quality, safety and efficiency

A workforce confidently using digital health technologies to deliver health and care

A thriving digital health industry delivering world-class innovation
My Health Record – key benefits

- Avoided adverse drug events
- Improved systems through secondary use of data
- Enhanced patient self-management
- Improvements in patient outcomes
- Reduced time gathering information
- Avoided duplication of diagnostic services
My Health Record – how does it work?

General Practice
Hospitals
Specialists
Pathology & DI
Allied Health
Pharmacist
Aged Care

My Health Record

Shared health summaries
Event summaries
Discharge summaries
Specialist letters
Pathology and diagnostic imaging reports
Prescription & dispense records
eReferrals
Road map to today

• Every Australian will get a My Health Record by 31 Jan 2019, unless they choose to opt out
• The Australian Parliament has passed legislation that has strengthened My Health Record’s privacy and security protections.
• The new legislations means that Australians can opt out at any time
My Health Record legislation highlights

- Law enforcement agencies need a court or similar order to access a record
- Access by insurers and employers is prohibited
- Parents removed as authorised representatives when a child turns 14
- Strengthened protections for people at risk of family and domestic violence
- A person’s record will be deleted when they opt out
Where to now?

**Consumers** decide if they want a My Health Record

**Increase** in clinical documents uploaded to My Health Record

**Behaviour change** in the way My Health Record is used

- **On track**
- **On track**
- **In progress**
My Health Record – latest national statistics

6.45 million consumers have registered (as at 13 Jan 2019)

15,315 healthcare provider organisations registered

10.67 million clinical documents uploaded

30.8 million medication prescription and dispense records uploaded

13 January 2018
My Health Record – secondary uses of data
The Framework

→ Released by the Minister for Health in 2018

→ Developed in consultation with consumers, clinicians, medical researchers & industry experts

→ Provides guidance for use of My Health Record system data

→ Appoints AIHW as the Data Custodian

→ Implementation plan is being developed by AIHW, Australian Digital Health Agency and the Department of Health.
My Health Record (MHR) System Data for Research and Public Health Purposes (secondary use) - working together to implement
MHR Data Governance Board
MHR System Information Sources

- Views
- Search
- Views
- Search
- Reports
MHR High Level System Architecture
What’s in the MHR?

- Each MHR is a collection of clinical documents for an individual from a number of different sources.
Clinical document

Header

Body

Section

Section

<recordTarget>

</recordTarget>

<author>

</author>

<structuredBody>

<section>

<text>

...</text>

</section>

<entry>

</entry>

<entry>

...</entry>

<text>

...</text>

<section>

<entry>

...</entry>

</section>

narrative

structured data

narrative

structured data
Narrative

- XML tags for **formatting** the display of information

```xml
<text>
  <paragraph styleCode="xFontSizeP=12 Bold">Diagnoses for Current Visit and Previous.</paragraph>
  <table border="1" width="100%">
    <thead>
      <tr>
        <th>Diagnosis</th>
        <th>Type</th>
        <th>Ranking</th>
        <th>Status</th>
        <th>Onset Date</th>
      </tr>
    </thead>
    <tbody>
      <tr>
        <td ID="PROBSUMMARY_1">Elevation of SaO2</td>
        <td>Discharge</td>
        <td>Primary</td>
        <td>Active</td>
        <td>14-Aug-2013</td>
      </tr>
    </tbody>
  </table>
  <table>
    <thead>
      <tr>
        <th>Problem</th>
        <th>Status</th>
        <th>Ranking</th>
        <th>Onset Date</th>
        <th>Classification</th>
        <th>Date Reported</th>
      </tr>
    </thead>
    <tbody>
      <tr>
        <td ID="PROBSUMMARY_2">Asthma</td>
        <td>Active</td>
        <td>Primary</td>
        <td>12-Aug-2013 13:36</td>
        <td>Medical</td>
        <td>12-Aug-2013</td>
      </tr>
    </tbody>
  </table>
</text>
```
Structured Data

- XML tags for computer processing of the information for data analysis and clinical decision support

```xml
<entry typeCode="COMP">
  <observation classCode="OBS" moodCode="EVN">
    <id root="b747d7c1-6924-4418-a555-c3c75a3e0de"/>
    <code>
      <originalText>Primary</originalText>
    </code>
    <value xsi:type="CD" display="Asthma" codeSystem="2.16.840.1.113883.6.96" codeSystemName="SNOMED CT"/>
  </observation>
</entry>

<entry typeCode="COMP">
  <observation classCode="OBS" moodCode="EVN">
    <id root="8e61c2-46bf-44dd-9046-580d4d626991"/>
    <code>
      <originalText>Primary</originalText>
    </code>
    <value xsi:type="CD" display="Oxygen saturation above reference range" codeSystem="2.16.840.1.113883.6.96" codeSystemName="SNOMED CT"/>
  </observation>
</entry>
```

Data coded using an international code system for clinical terminology
Secondary use applications in the UK – What types of confidential data do researchers need?

Figure 1. Type of confidential data requested through the U.K CAG

Figure 2. Pearson correlation coefficient of data types requested through the U.K CAG
Secondary use applications in the UK
What is the purpose for release of data?

- Ethics approved research
- Preventive Health
- Medical diagnosis
- Care and treatment
- Service mgmt
- Informing direct care
Secondary use applications in the UK
Who is applying for data?

Number of applications 2013-18 by applicant type (CAG)

- University: 225
- Trust (PHN): 80
- Hospital: 50
- Collaborative application: 50
International examples of data use from similar systems

→ Large scale studies
→ Cohort Studies
→ Case Control Studies
→ Purposive sampling
→ Policy evaluation
→ Methodological Research
→ Replication Studies

→ Study patterns of diseases in the population;
→ Identify causes of disease and their impact;
→ Develop and evaluate preventive and therapeutic strategies, health services, programs, and policies;
→ Assess data quality;
Legislation changes passed but yet to commence

Working on metadata

Technical preparations for the data access and storage

Analysis challenges

Considering how to provide secure access to data
Key considerations on the journey

→ Collect once, use many
→ Data standards are essential to combine data from a wide range of systems
→ Policy/legislation/regulation must be in place to ensure necessary checks and balances
→ Build and maintain public trust in the governance arrangements in place
Key considerations on the journey

→ Manage expectations of stakeholders about what data will be available
→ Ensure the data is fit-for-purpose for the use to which it will be put
→ Assess and report on the quality of the data, including the coverage, completeness, accuracy,
→ Open and transparent reporting on the uses of data to demonstrate the value case
Vision for My Health Record System Data

- Valuable information on Australia’s health system
- Insights about the effectiveness of services and treatments

- To ensure that patients receive evidence-based care
- To ensure that future health investment is directed at those who need it most
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Questions?