



Australian Government

Australian Institute of  
Health and Welfare

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

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The AIHW logo, with the letters A, I, H, and W in different colors (blue, green, red, and purple respectively).

Stronger evidence,  
better decisions,  
improved health and welfare

# What is a My Health Record?

→ <https://youtu.be/caYPHvufYgQ>





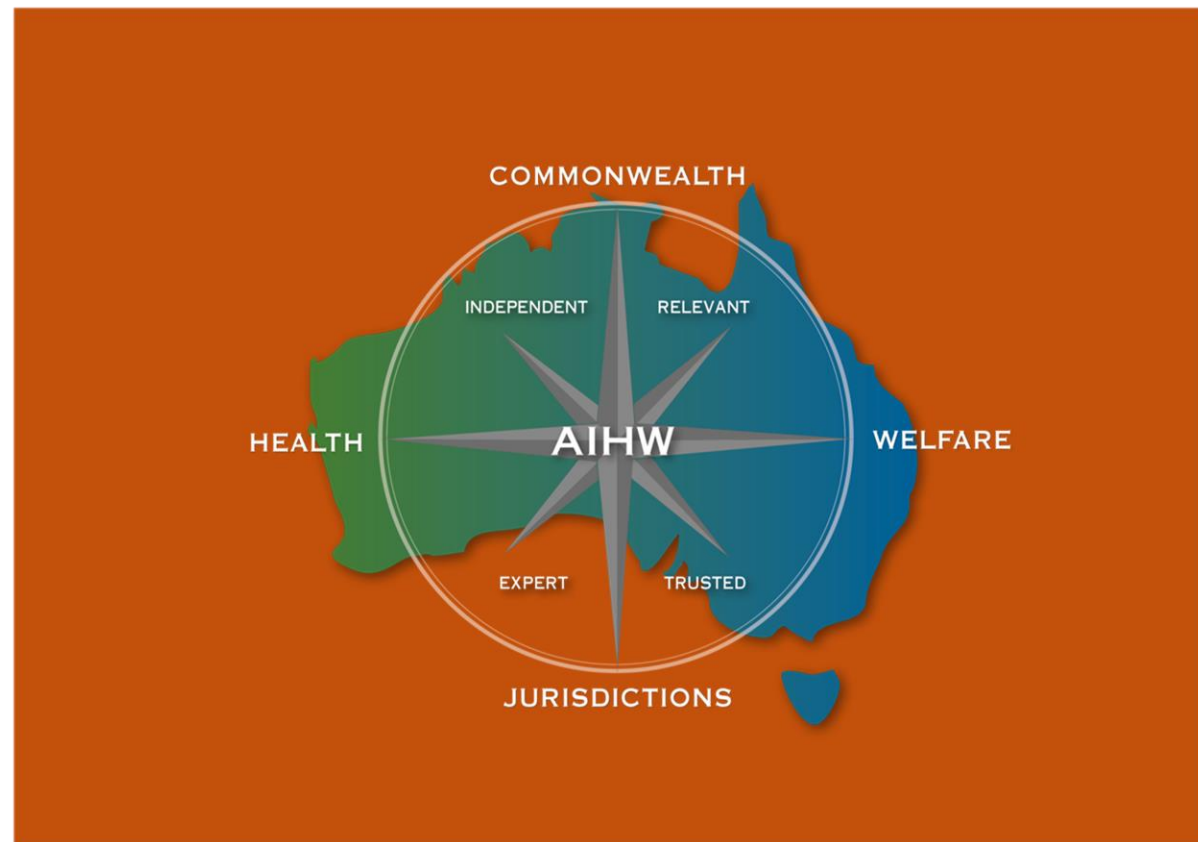
## Who we are

- 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
- Drivers of data improvements
- Expert sources of valued-added analysis
- Champions for open and accessible data and information
- 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...

The screenshot shows the MyHospitals website interface. At the top, the Australian Government logo and 'MyHospitals' branding are visible, along with the tagline 'Informing patients, supporting clinicians, driving improvements'. Navigation links include 'hospitals', 'Compare hospitals', 'About the data', and 'About MyHospitals'. The main content area features a large image of a doctor attending to a patient, a search bar for 'Your location', and a 'Latest reports' section. The 'Latest reports' section includes a report released on 16 February 2017 about healthcare-associated *Staphylococcus aureus* bloodstream infections in 2015-16, and a new interactive table to compare rates of these infections for public hospitals. A 'View all reports' button is present. Below this, the 'Latest data' section mentions healthcare-associated *Staphylococcus aureus* bloodstream infections in 2015-16 and provides a 'Download the data' link. An overlay on the left side of the screenshot is a report titled 'Australia's hospitals 2016-17 at a glance' from the Australian Institute of Health and Welfare (AIHW).

This block contains a collage of various AIHW reports and infographics. The reports include:

- Admissions into aged care GEN AGED CARE DATA 2016-17**: An infographic showing that over 215,000 people entered residential or transition care in 2016-17, and that 2 in 3 people entering aged care moved into residential care.
- Analysis of bowel cancer outcomes for the National Bowel Cancer Screening Program 2018**: A report from the Australian Institute of Health and Welfare.
- 105 days**: An infographic stating that the median number of days between being approved for and entering permanent residential care was 105 days.
- 39%**: An infographic stating that the number of people entering home care has increased over the last 5 years by 39%.
- GEN-agedcaredata.gov.au**: A URL at the bottom of the collage.

The AIHW logo is also visible in the bottom right corner of the collage.

## 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



Prebirth



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

40%

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



Adult



Digital tools make it easier to access services remotely

\$1.2B

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



Older Adult



Medicines information available via My Health Record reduces safety risk

14%

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



Senior



People and their clinicians will be able to see results of previous tests

# FUTURE



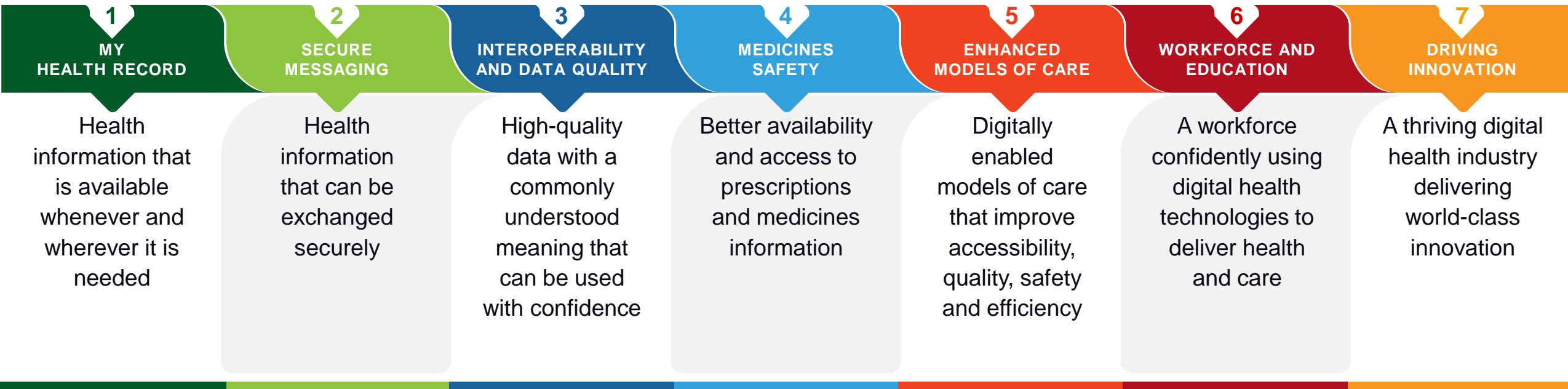
Australian Government  
Australian Digital Health Agency



My Health Record

# National Digital Health Strategy – roadmap for delivery

Co-designed with all states and territories and agreed by COAG Health Council



# My Health Record – key benefits



Avoided adverse  
drug events



Improved systems  
through secondary  
use of data



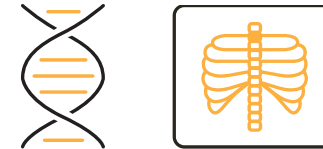
Enhanced patient  
self-management



Improvements  
in patient outcomes



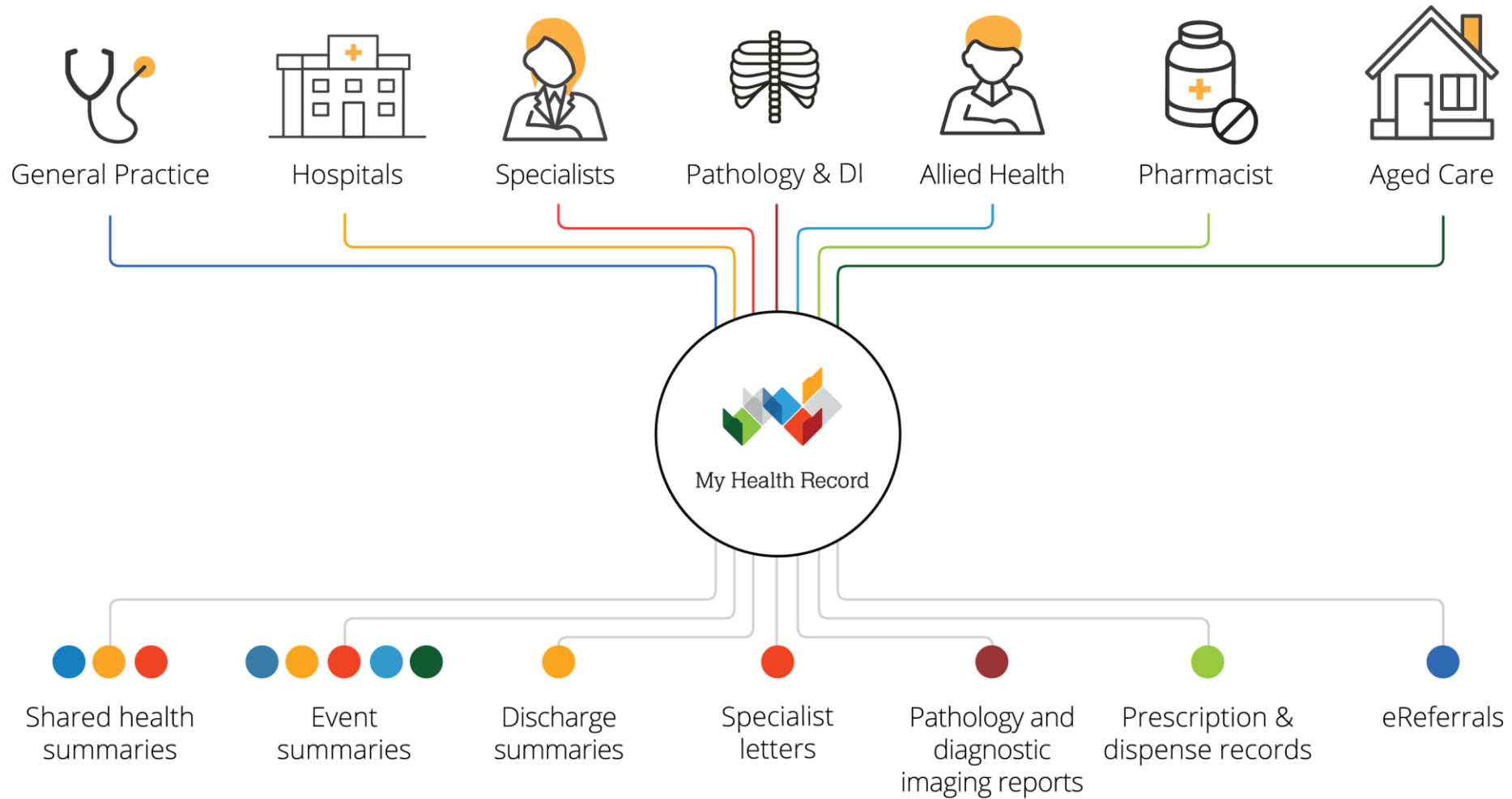
Reduced time  
gathering information



Avoided duplication  
of diagnostic services



# My Health Record – how does it work?



## 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

On track



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

On track



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

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



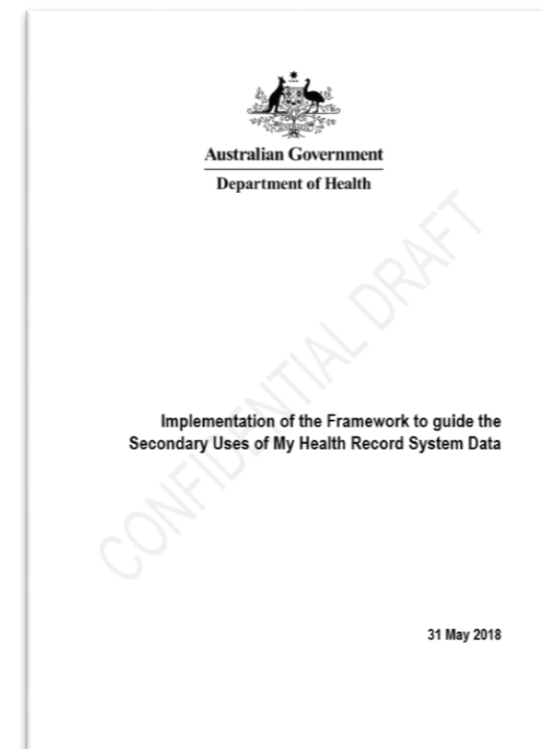
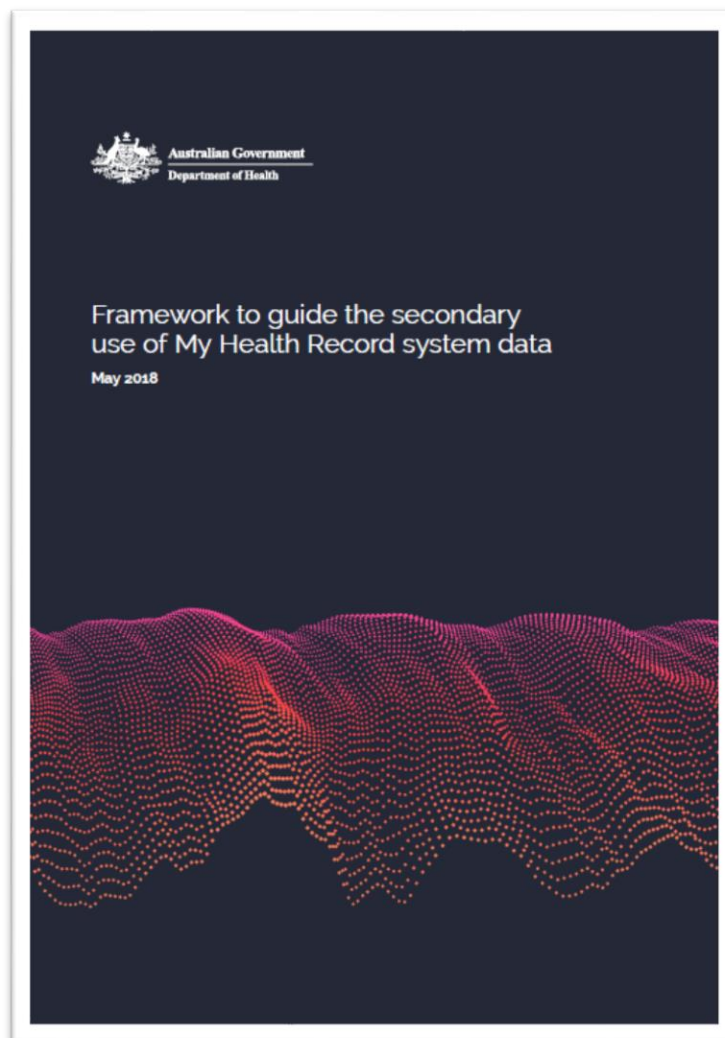
**10.67 million** clinical documents uploaded



**30.8 million** medication prescription and dispense records uploaded

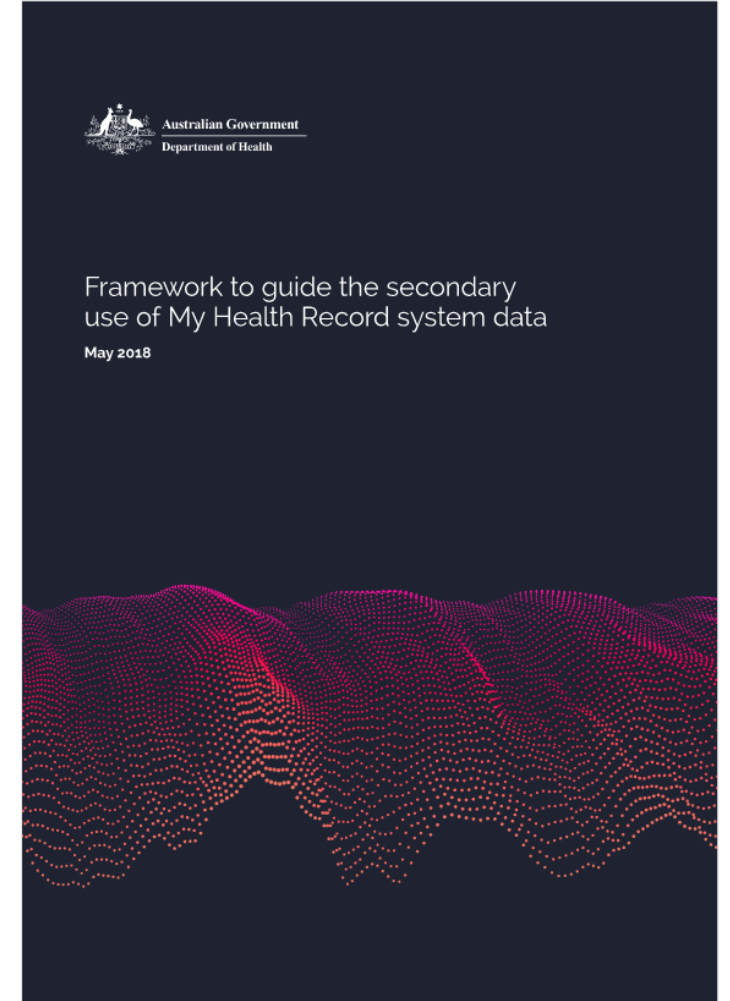
13 January 2018

# My Health Record – secondary uses of data

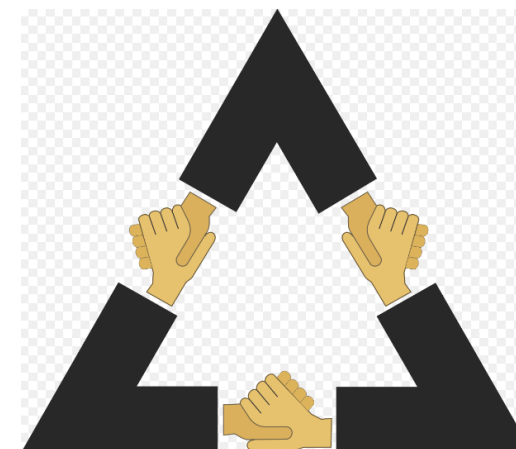
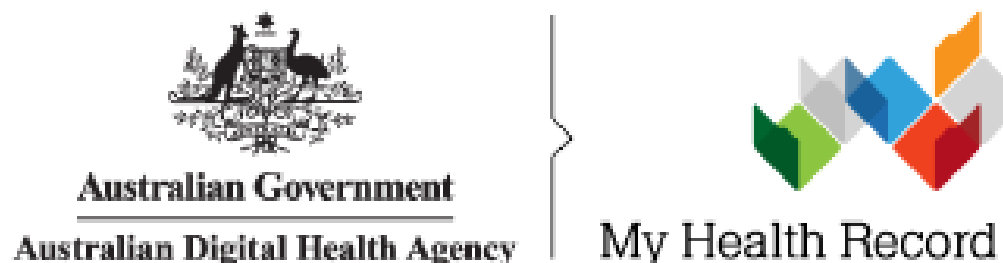


# The Framework

- 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



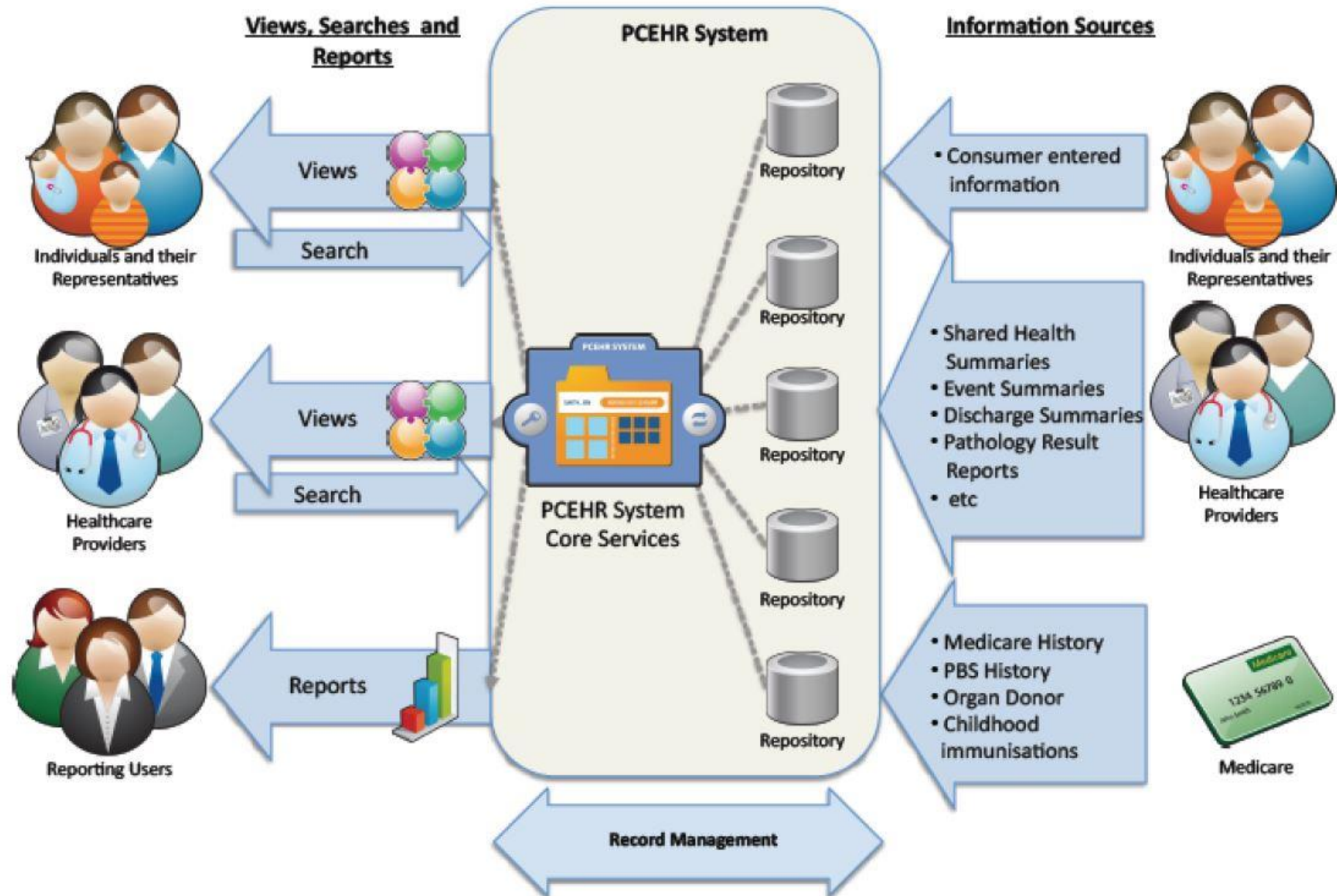




# MHR Data Governance Board

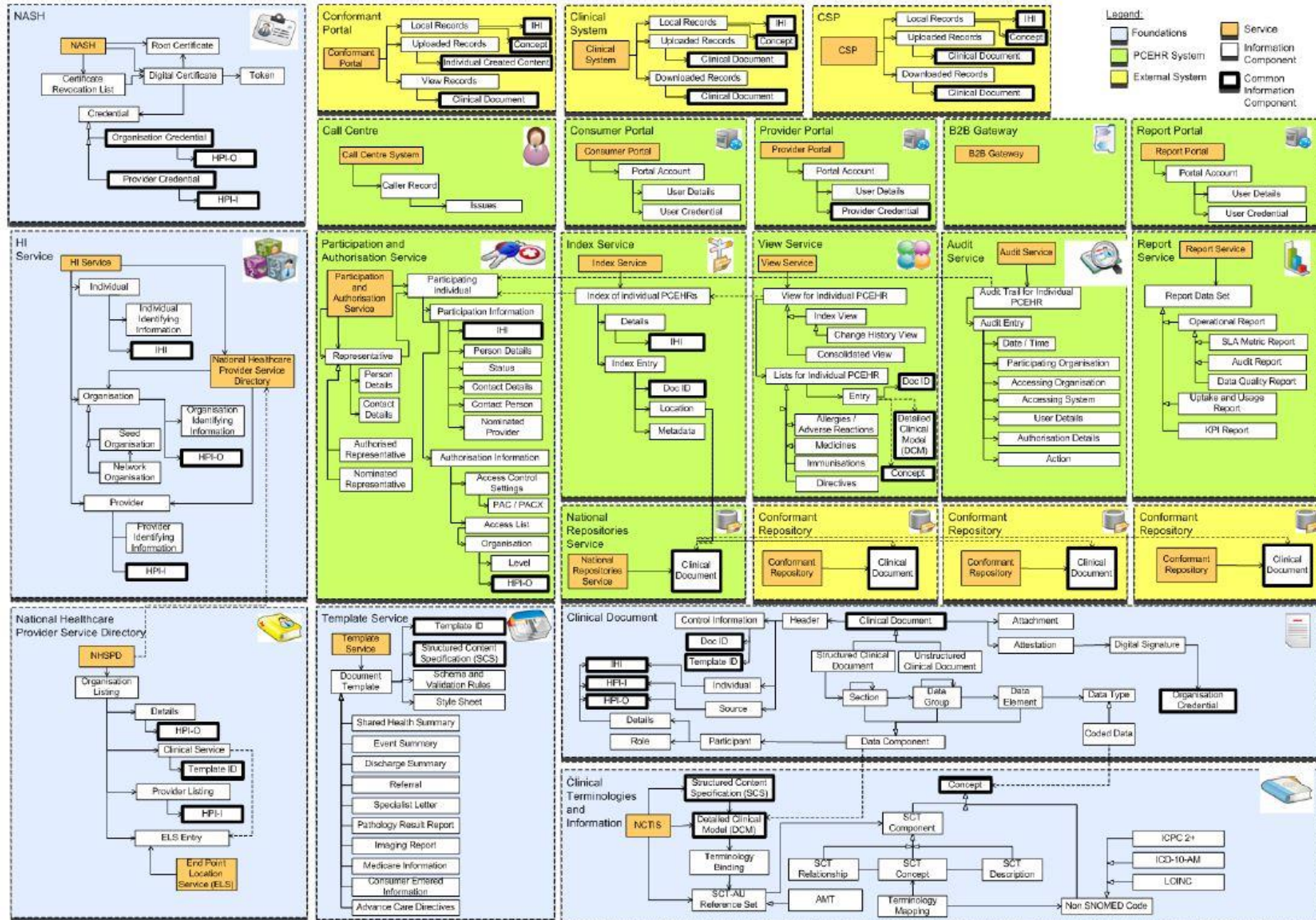


# MHR System Information Sources





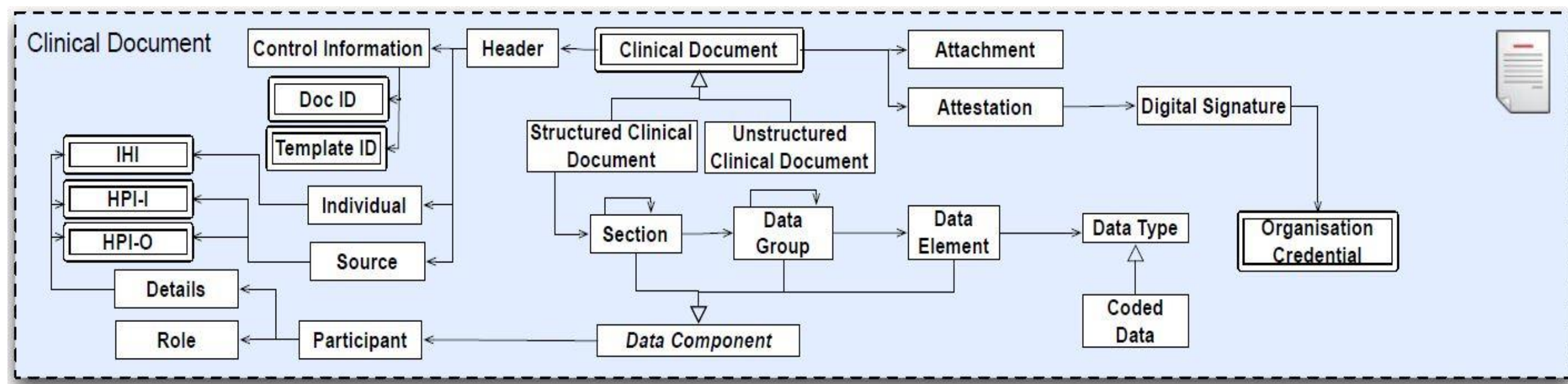
# MHR High Level System Architecture





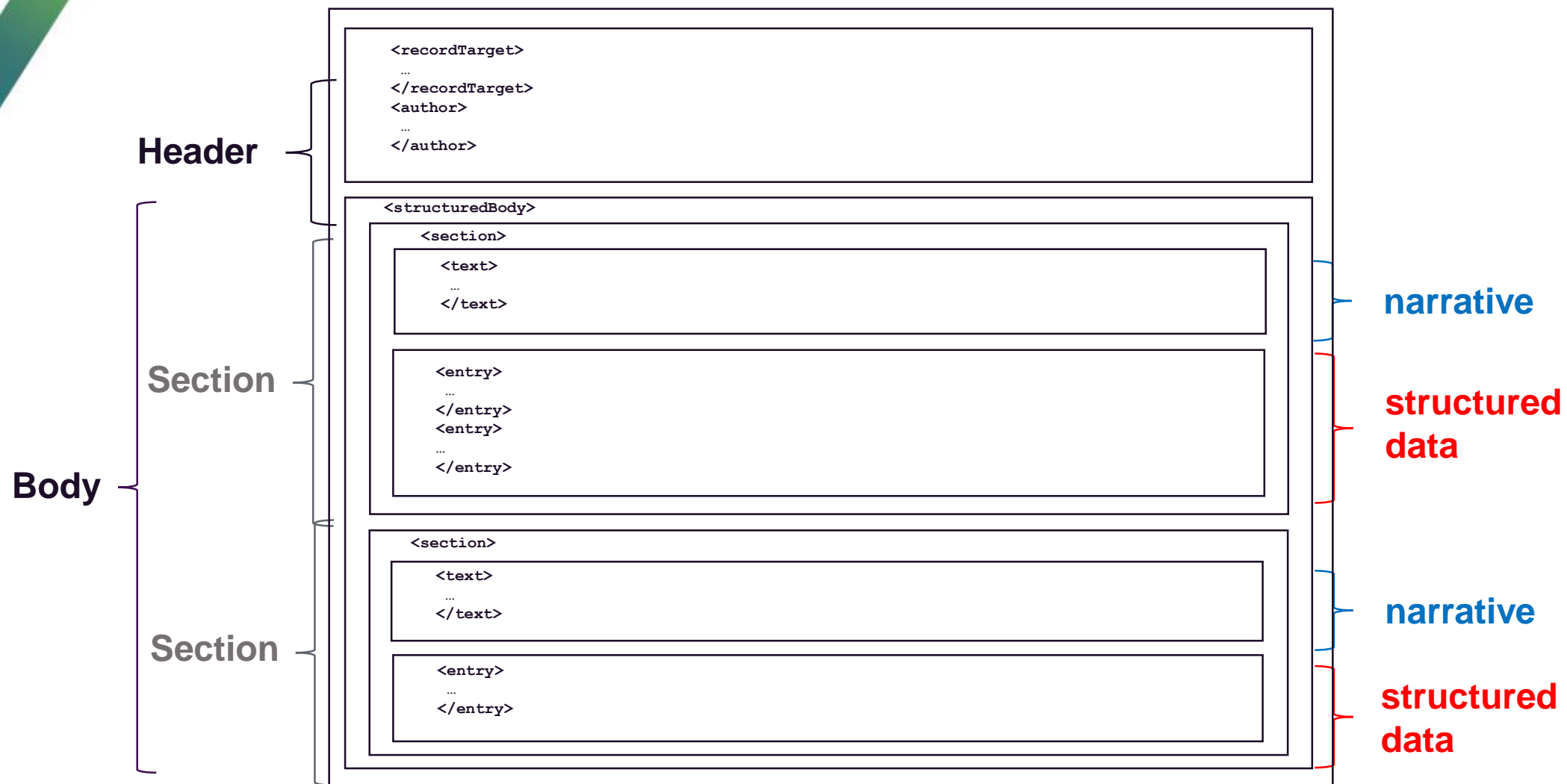
# What's in the MHR?

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





# Clinical document



# Narrative

- XML tags for *formatting* the display of information

```
<text>
  <paragraph styleCode="xFontSizePx12 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>
  <paragraph styleCode="xFontSizePx12 Bold">Problems for Current Visit and
    Previous.</paragraph>
  <table border="1" width="100%">
    <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

```
<entry typeCode="COMP">
  <observation classCode="OBS" moodCode="EVN">
    <id root="b747d7c1-6924-4418-a555-cc3c75a3eede" />
    <code>
      <originalText>Primary</originalText>
    </code>
    <value xsi:type="CD" code="195967001" displayName="Asthma" codeSystem="2.16.840.1.113883.6.96" codeSystemName="SNOMED CT" />
  </observation>
</entry>
<entry typeCode="COMP">
  <observation classCode="OBS" moodCode="EVN">
    <id root="8efe61c2-46bf-44dd-9046-58d04d626991" />
    <code>
      <originalText>Primary</originalText>
    </code>
    <value xsi:type="CD" code="276735007" displayName="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

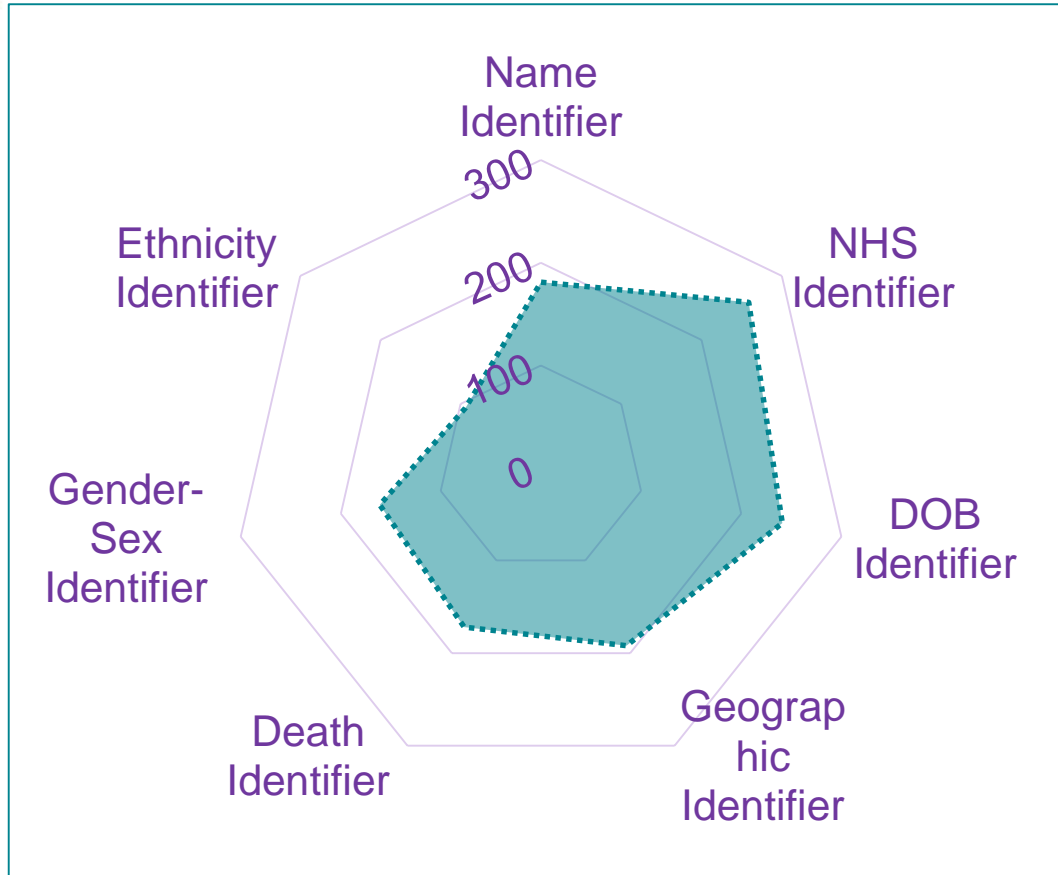
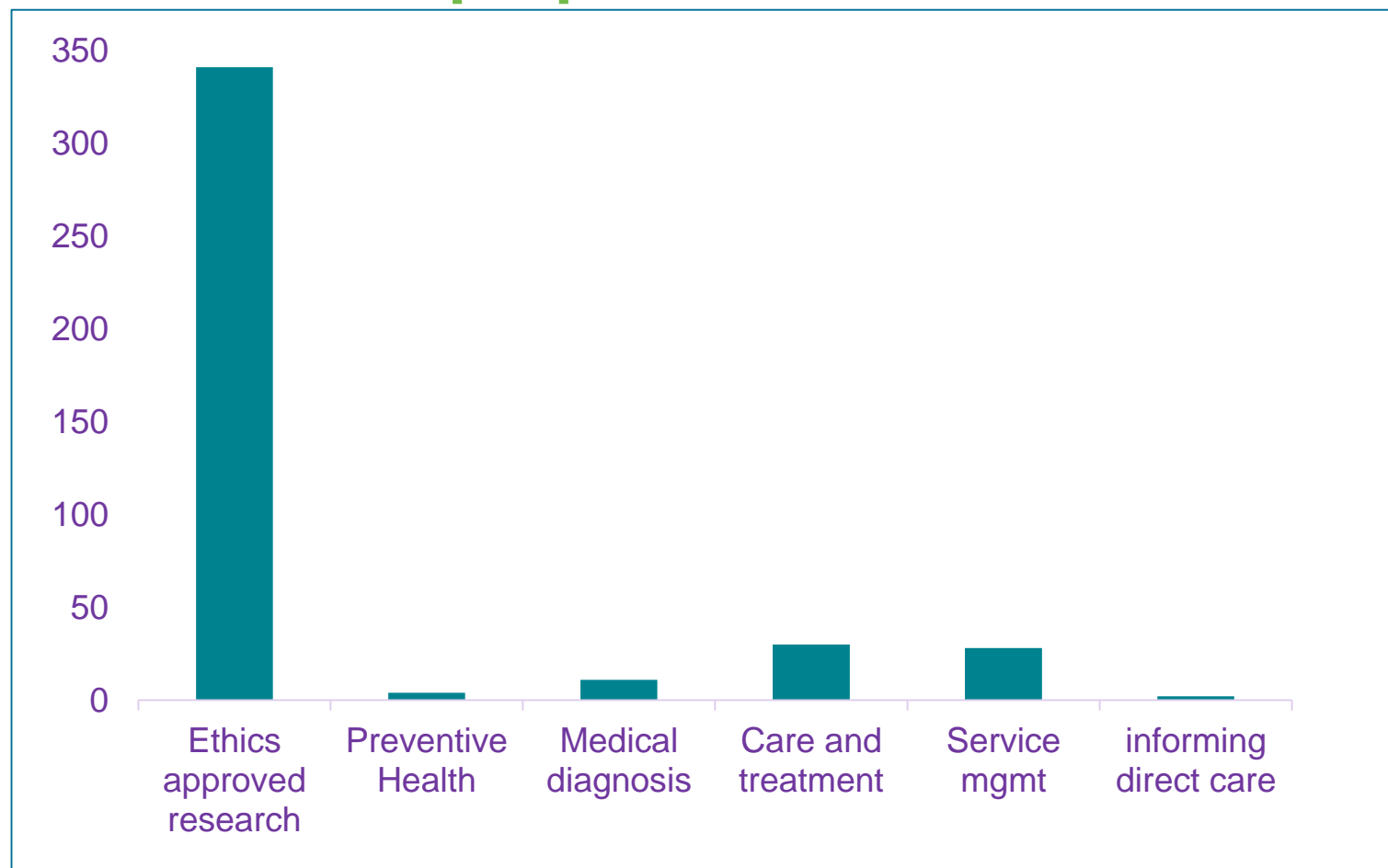


Figure 2. Pearson correlation coefficient of data types requested through the U.K CAG

	Name	NHS #	DOB	Geograph	Death	Gender-Sex	Ethnicity
Name	1						
NHS #	0.32	1					
DOB	0.5	0.5	1				
Geograph	0.53	0.3	0.55	1			
Death	0.07	0.16	0.39	0.08	1		
Gender-Sex	0.12	0.33	0.40	0.21	0.17	1	
Ethnicity	-0.09	0.25	0.37	0.26	0.21	0.89	1

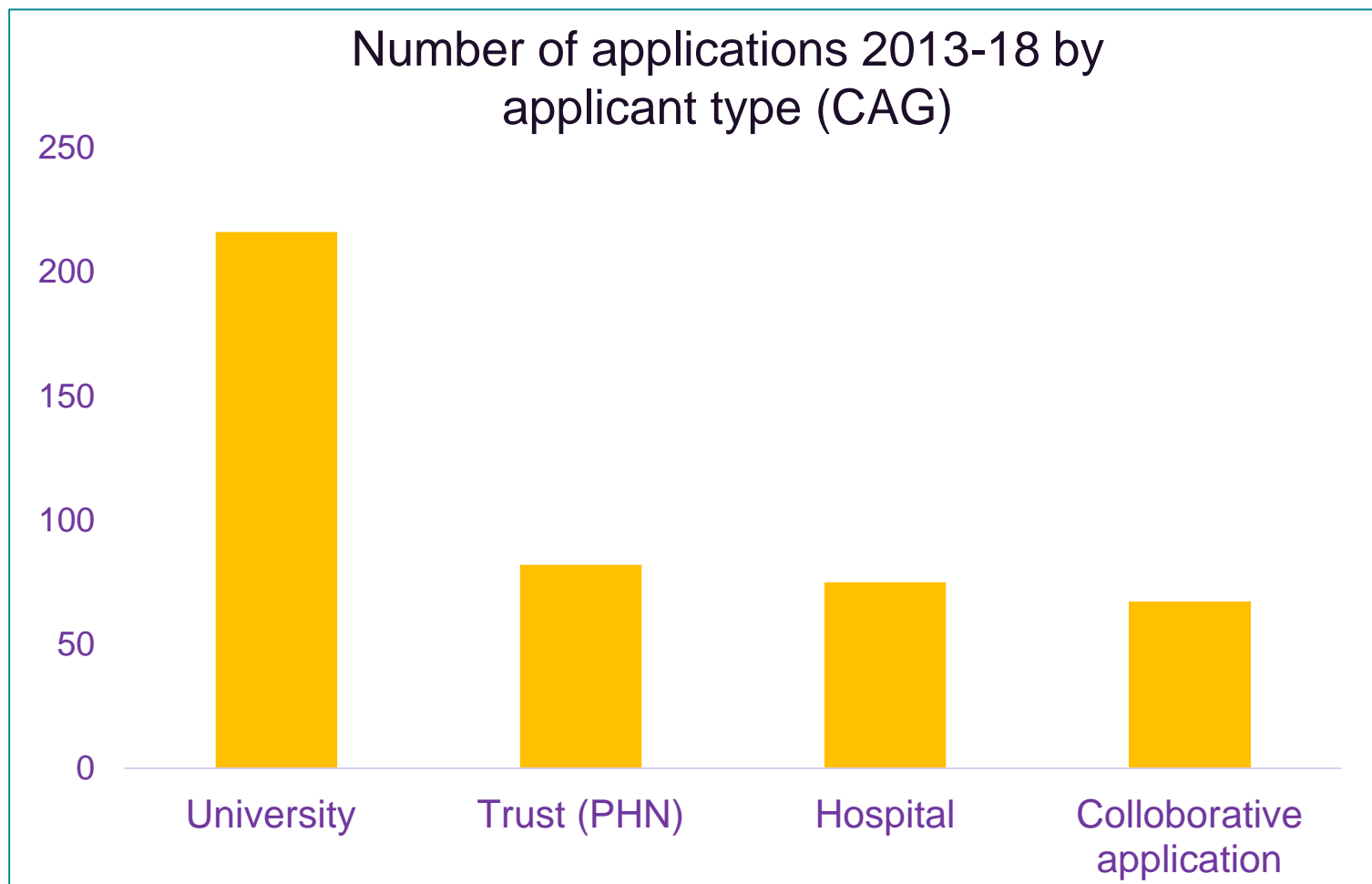
## Secondary use applications in the UK

### What is the purpose for release of data?



# Secondary use applications in the UK

## Who is applying for data?

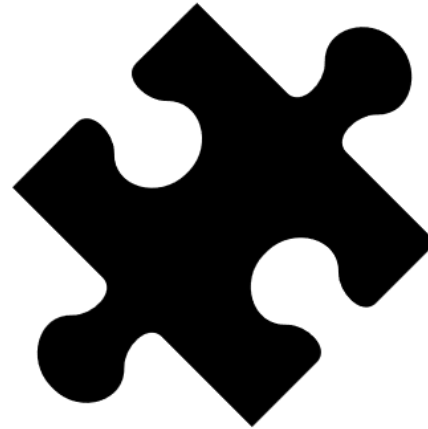


# International examples of data use from similar systems



Canadian Institute for Health Information  
Better data. Better decisions. Healthier Canadians.

- 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;

# Where to from here?

- **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

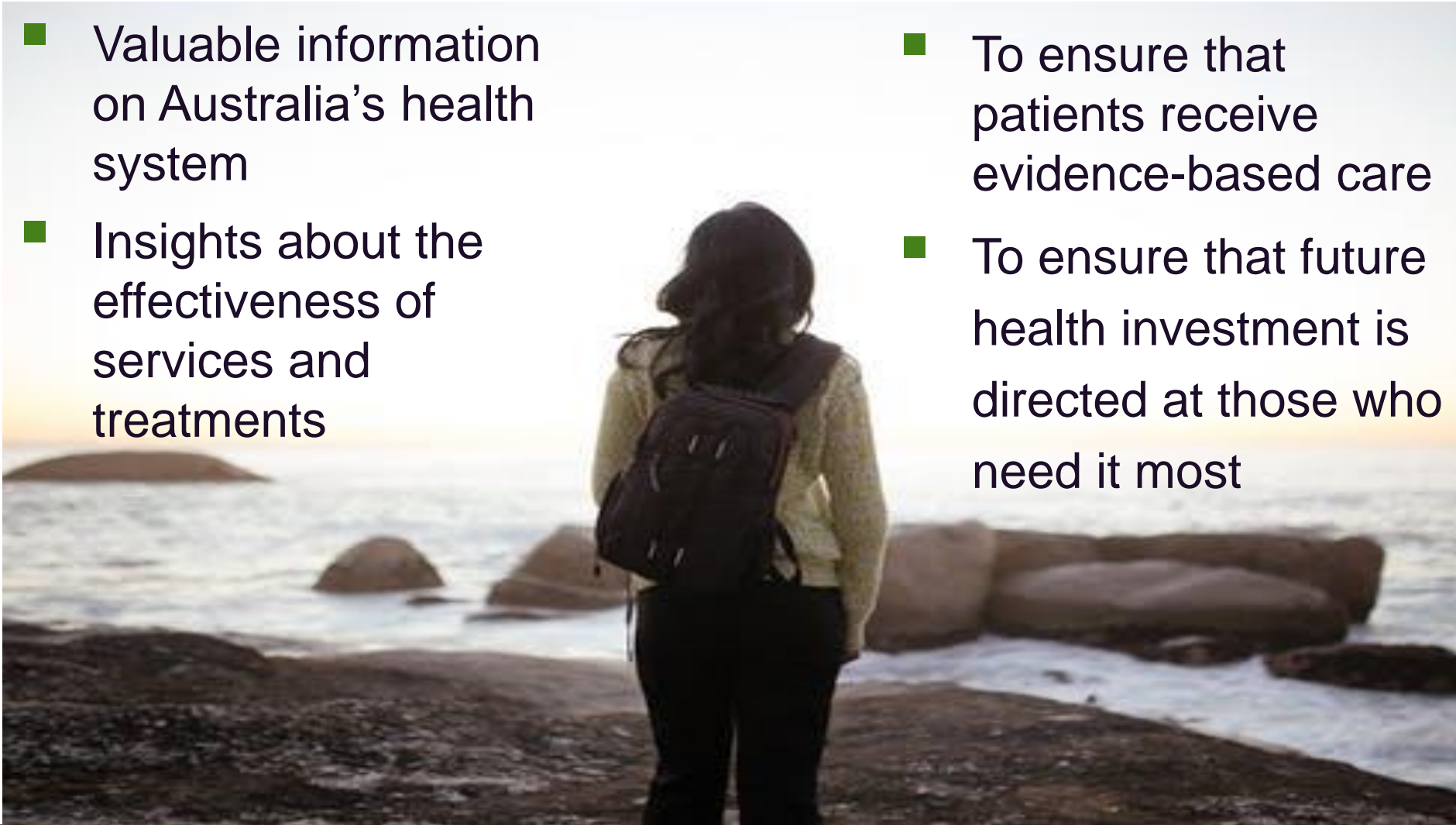


## Key considerations on the journey

- 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?

