

The forefront of health informatics:
Partnering with PHNs for a comprehensive view of Australia's health care

Dr Zoran Bolevich

Chief Executive Officer

Australian Institute of Health and Welfare







The AIHW acknowledges the Traditional Owners of Country throughout Australia and recognises their continuing connection to lands, waters, and communities.

We pay our respect to the people, the cultures, and Elders past and present.

# About us



An independent national information and statistics agency within the health portfolio



At the forefront of cross-jurisdictional data linkage **6**—0 since the 1980s



Publishes more than 400 data products a year



Maintains and administers specialised data standards and classifications



Deep partnerships with Commonwealth agencies, as well as states and territories



Collaborates on data projects, provides data and information to support policies and decision making







#### Vision

#### Stronger evidence, better decisions, improved health and welfare for all Australians



# Stakeholder outcomes

- People and organisations have comprehensive and trusted health and welfare data they can engage with
- AIHW data and evidence is used to inform policy and guide service planning and delivery
- Performance measurement, evaluation and improvement is enabled by the AIHW's data and analysis
- High quality research is enabled by integrated, secure and timely data



# **Organisation** goals

- A trusted leader in health and welfare data and analysis
- Innovative producers of data sets and analysis
- A strong strategic partner
- Recognised for our organisational excellence
- Recognised by First Nations people and organisations as an exemplary partner and organisation



#### **Enabler priorities**

- Streamlined data governance, integration and sharing
- Effective communication, engagement and collaboration
- Highly skilled workforce
- Contemporary digital platforms and tools
- Optimised business processes and project delivery



#### **Core functions**

- Develop, collect and curate health and welfare data
- Create, share and facilitate access to analysis, information and reports
- Conduct, promote and support research on people's health and welfare
- Coordinate and encourage high-quality and comparable data through development of standards and adoption of classifications
- Promote effective use of data and sector-wide development of analytical capabilities



#### **Strategic context**

- Multiple and inter-related health and social policy reforms
- Complex decision-making environment
- Complex legal, governance and privacy environment

- More diverse stakeholder needs
- Rapid technological advancements bringing new opportunities and risks
- Dispersed data and information sources
- Fiscal constraints
- Greater focus on monitoring and evaluation
- Increased focus on measuring outcomes
- Increased demand for integrated data

# Outcomes supported by AIHW's data and services

- Informing the policy-making cycle
- Guiding and supporting planning and delivery of services
- Monitoring and assessing performance
- Informing workforce planning
- Evaluating outcomes and identifying improvement opportunities
- Informing the public
- Enabling research







# Data Standards as a key enabler

National Minimum Data Sets (NMDS) are a core set of data elements agreed by the National Health Information Management Group for mandatory collection and reporting at a national level.

**AIHW manages 20 NMDSs** (and 100+ other data sets at various levels of standardisation).

### We hold NMDS for:

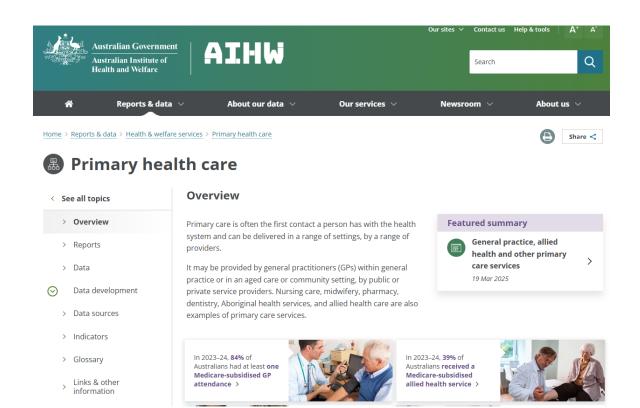
- admitted patient care
- disability services
- child protection
- residential and community mental health
- youth justice
- specialist homelessness services
- non-admitted emergency care
- alcohol and other drug treatment services





# **AIHW's current Primary Care activities**

- Medicare-subsidised GP, allied health and specialist health care across local areas, using MBS data
- Potentially preventable hospitalisations (PPH)
  in Australia by small geographic areas, using
  hospitals data
- Use of emergency departments for lower urgency care, using ED data
- PIPQI reporting: 10 Quality Improvement Measures (QIMs) across 6,095 practices for over 20 million regular clients
- Weekly transfer of Urgent Care Clinic data between the Department and PHNs via the Primary Health Insights platform
- Secondary use of My Health Record data, in partnership with the Australian Digital Health Agency [under development]











Trends which are increasing availability and use of data in Health



#### **Digital advances**

- Digital 'systems of record' more prevalent and more integrated
- Interoperability agenda (including the use of national identifiers)

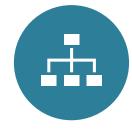


# Advances in data management and analytics

- Data extraction tools / capabilities
- Modern Data Analytics Platforms
- Machine learning and Al / LLM



Maturing of data linkage capabilities



'Five Safes' and other contemporary data governance models







- Convergence of digital health and data analytics
- Greater demand for integrated data insights (data integration)
- The rise of Al

Optimising Workflows
Resource Allocation & Staffing
Supply Chain Management
Revenue / Activity Management
Automation

Operational Efficiency & Fin. Performance

Real-time Analytics Predictive Analytics Prescriptive Analytics Enhanced Diagnostics Clinical Decision Support Personalised Medicine

Advanced Analytics and AI/ML

Prevention and Early Intervention
Personalised Care Plans
Improved Patient Monitoring
Integration of Care
Patient Experience Analytics

Data for Enhanced Patient Care

Safety & Quality Metrics
Patient Reported Outcome
Measures (PROMs)
Comparative Analysis
Health Equity & Social
Determinants of Health

Focus on Outcomes & Value Based Care

Data Integration
FHIR Adoption
Cloud Adoption
Data Quality Management
Enterprise Data Lakes
Cyber Security

Data Infrastructure & Interoperability



# How we are applying it

Al Adoption at the AlHW

Data linkage improvement

Data quality improvement

**Data clustering** 

**Data validation** 

Data classification & coding

Information extraction from unstructured data

Data de-identification

Data early estimation

Risk factor & association analysis

# Integration of health data – the National Health Data Hub (NHDH)



State/territory notifiable diseases data: COVID-19 cases



Medicare Consumer Directory (MCD)



National Notifiable Diseases Surveillance System (NNDSS)



National Death Index (NDI)



National Aged Care Data Clearinghouse: aged care data (NACDC)



Australian and New Zealand Intensive Care Society (ANZICS)



Medicare Benefits Schedule (MBS)



Pharmaceutical Benefits Scheme (PBS)



National Hospital Morbidity Database: admitted patient care data (NHMD)



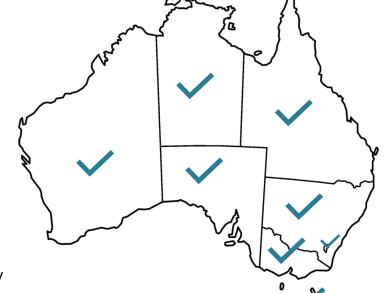
Australian Immunisation Register (AIR)



National Non-Admitted Patient Emergency Department Care Database: emergency department presentations (NNAPEDCD)

#### **Progressing towards the inclusion of:**

- Cancer data
- Cancer screening data
- COVID-19 cases from the National Notifiable Disease Surveillance System
- Mental health data
- Perinatal data









## **Examples of NHDH-enabled projects**

The last year of life: patterns in health service use and expenditure

Medication use for secondary prevention after coronary heart disease hospitalisations: Patient pathways using linked data

Strengthening national COPD monitoring using linked health services data

Younger onset dementia: new insights using linked data

Estimating the incidence of stroke and acute coronary syndrome using the National Integrated Health Services Information Analysis Asset

Hip fracture care pathways in Australia

Treatment pathways for people hospitalised for acute coronary syndrome

Health service use for patients with traumatic brain injury

Examination of hospital stays due to family and domestic violence 2010–11 to 2018–19

Predicting early dementia using Medicare claims: a feasibility study using the National Integrated Health Services Information Analysis Asset

Health service utilisation by people with dementia in Australia





# **Data flows conceptual framework**

## **Supply once**

### **Use many times**

Dependent on new approvals for each purpose



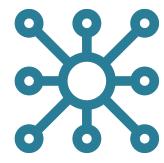
Data supplied once, ideally directly from systems of record



AIHW linkage system



AIHW managed integrated data access



Interoperable linkage spines for external integration





## **Opportunity**



Leverage the potential of data integration and 'big data' to create patient-centric data ecosystem



Align primary and secondary uses of data to reduce administrative burden and achieve optimal data flows



Use AI to improve data quality, integrity and consistency, and bring new types of data into the ecosystem







# Limitations and challenges

'Despite the potential for policies to be based on evidence, in reality an effective connection with many types of research evidence in policy-making remains elusive.'

#### **DATA & TECHNOLOGY**

- Data gaps
- Data quality
- Fragmentation
- Double handling
- Timeliness
- (Under) investment in data analytics tools & infrastructure

#### **PEOPLE & PROCESS**

- Complex governance and legislative frameworks
- Legitimacy and public trust
- Lack of skill and capacity
- Cognitive biases
- Competing stakeholder interests / priorities
- Ethical and accountable use of data and algorithms







# Building capacity for a data-driven health system



Supporting active use of data and insights for quality decision-making and continuous improvement (and shifting away from current focus on targets)



Professional development programs, communities of practice and other capability building strategies



Adoption of contemporary technologies and interoperability to improve quality, timeliness and integration of data



Harmonising legislation and evolving frameworks for governance, access and use of data



Strengthening collaboration and leveraging collective expertise and capabilities of jurisdictions, PHNs and service providers



Strategic investment in data platforms, tools and capabilities





The Gaps project (informing a new Health System Performance Assessment framework)

Action areas to address persistent gaps in performance assessment

#### Interfaces

**Main sticking** point:

Current definitions and are not useful and crude

#### Recommendatio

Develop nationally agreed health system interfaces performance measures

#### DDOP\*

**Main sticking** point: No national definition or

consistency in

data collection

#### Recommendatio

Standardised quarterly national census reporting of DDOP

\* DDOP = Delayed Discharge of Older Patient

## **Primary**

care **Main sticking** point:

Technical challenges with transferring data to other platforms and requires buyin from data custodians for secondary use

#### Recommendatio

Establish a national GP data collection and commence routine reporting

#### Workforce

**Main sticking** point:

Insufficient resources for meaningful interpretation of existing data

#### Recommendatio n:

Routine reporting from a national linkage system that includes workforce data

**CRITICAL ENABLERS** 

#### **Patient** reported measures

**Main sticking** 

point:

No agreement of suitable measures and the cost of infrastructure to transfer data

#### Recommendatio

n: Aggregation and reuse of existing **PREMs** collections and leverage off

#### conditions where

there is some

Harness existing data – National consistency – Practice translation – People-centred – Coordinate effort – Governance

#### **Preventive** health

**Main sticking** point:

Lack of long-term commitment to reporting and inconsistent national data

#### Recommendatio

Secure funding for the Aust. Burden of Disease Study and consistent reporting of public health spending

#### Unmet need

Main sticking point: No agreed

definition

#### Recommendatio

n: Develop a national model for health service planning



# Addressing data gaps: In partnership with PHNs



Working together to understand key gaps and opportunities for improvement. This must build on PHNs' existing capabilities and initiatives.



Undertaking general practice data demonstration projects. AIHW taking a learning approach.



Working in partnership with PHNs to develop pathways to national primary care data collection.



Technical co-lead on the National Primary and Acute Care Data Linkage Project.





# General practice data demonstration projects

#### **Project 1: Dementia (COMPLETE)**

- Aggregate data: 17 Primary Health Networks
- Towards a national primary health care data collection – dementia demonstration project, About - Australian Institute of Health and Welfare – released Jan 2025

#### **Project 2 (UNDERWAY):**

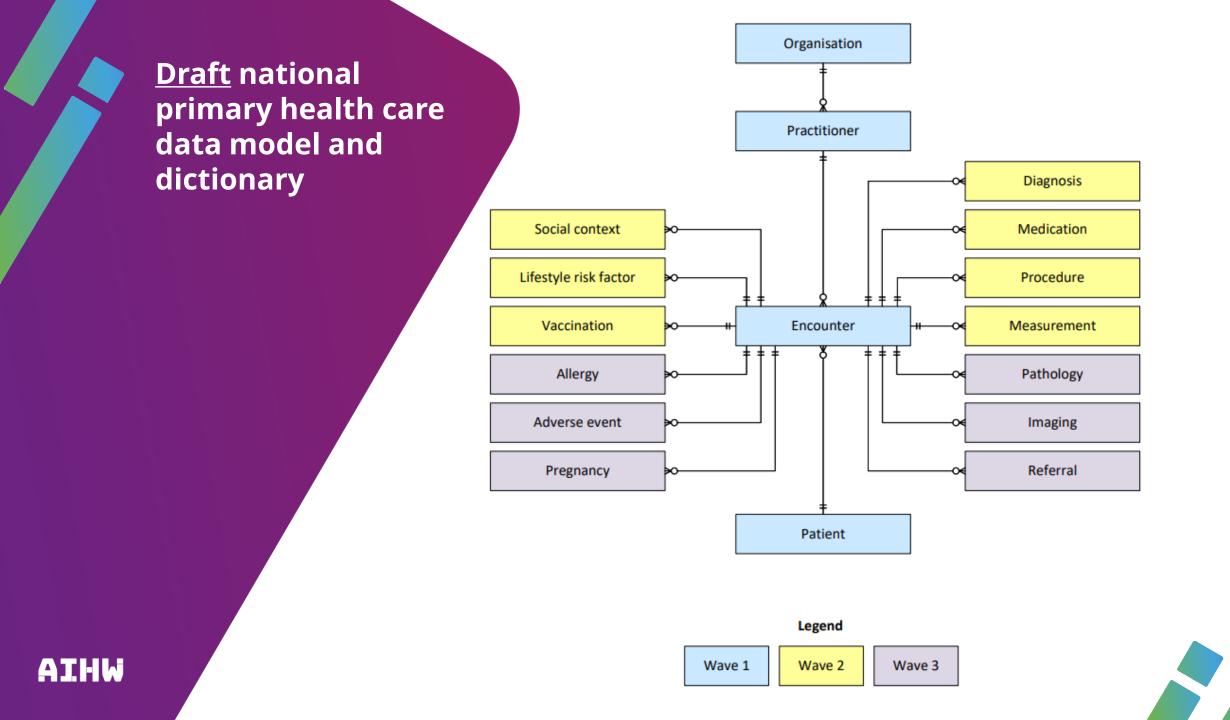
- Proof of concept using deidentified unit record data with Western Australian Primary Health Alliance (WAPHA)
  - Primary care and physical health outcomes of people diagnosed with a mental illness
  - Exploring prevalence of select conditions to inform burden of disease and health expenditure estimates

#### Other projects (UNDERWAY):

- Testing automated coding of 'reason for visit' data
- Accessing more granular data via curated datamart from PIPQI measures
- Investigating the usefulness of general practice data for closing data gaps in sexual & reproductive health







## **Next steps?**



Joint governance with PHNs and the Department of Health Disability and Ageing (discussions underway)



Development of a standard data model and data dictionary (underpinned by terminology and classifications), building on what has already been achieved



Targeted investment in data analytics platforms and tools



Joint capability building (developing data analytics workforce)



Supporting active use of data and insights for quality decision-making







# Imagine a health care system where...



**PHNs** have a complete and current picture of primary care services in their regions and how this compares on a national level



GPs and primary care teams receive regular, relevant and meaningful information about the health of their patient cohort, and the quality of services they provide to patients



More recent **policy** initiatives such as Urgent Care Clinics can be evaluated for their effectiveness as a by-product of routine clinical activity



**Research** teams have secure access to de-identified, linked data sets for advanced research projects









# Thank you



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**Australian Institute of Health and Welfare (AIHW)** 



www.aihw.gov.au



ceo@aihw.gov.au primaryhealthcare@aihw.gov.au