



# Breaking Data Linkage Barriers: Understanding Impediments to Routinely Linking Clinical Quality Registries with Administrative Data

Australasian Association of Bioethics & Health Law

L. Davis | 7 – 9 December 2025 | Aotearoa / New Zealand



**PHRN** Population  
Health  
Research  
Network

**NCRIS**  
National Research  
Infrastructure for Australia  
An Australian Government Initiative

# Clinical Quality Registries (CQRs)

- Quality assurance
- Research





# Constraints

- Feasibility
- Utility
- Sustainability



## Linked Data

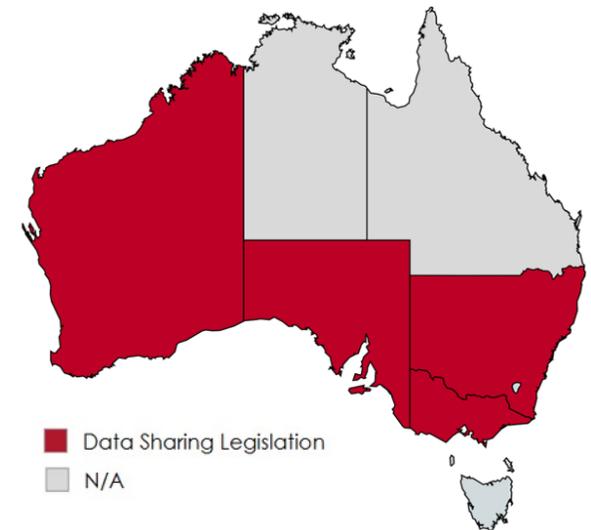
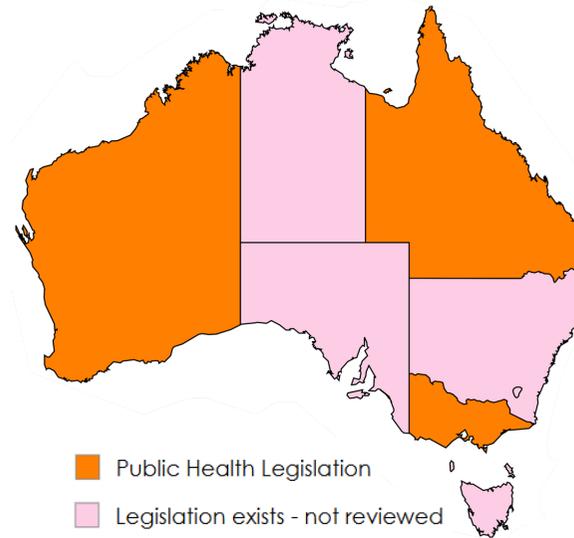
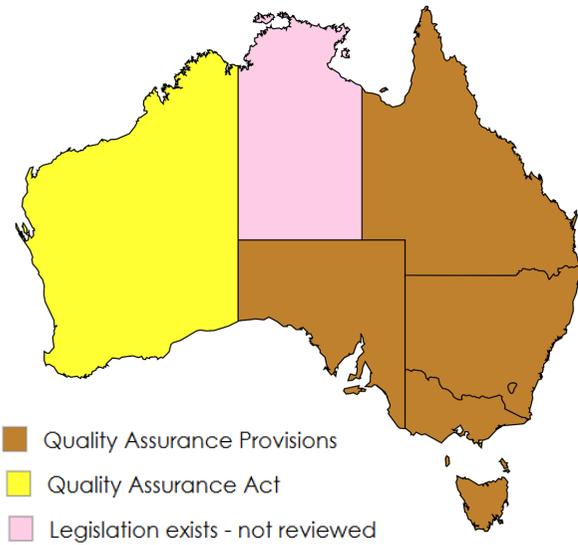
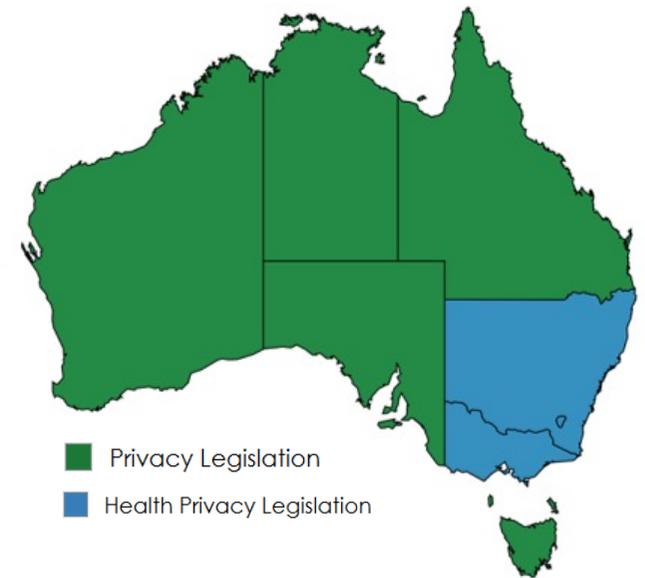
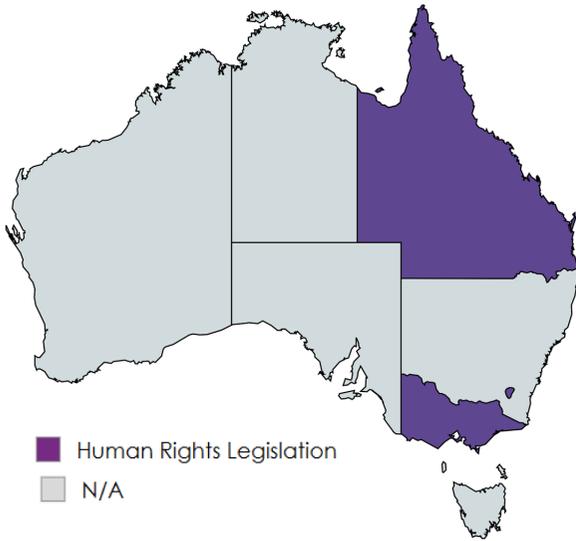
- Access to administrative data collections
- Population level-insights using a privacy preserving process
- Significant benefits for research and policy making



## Project Aims

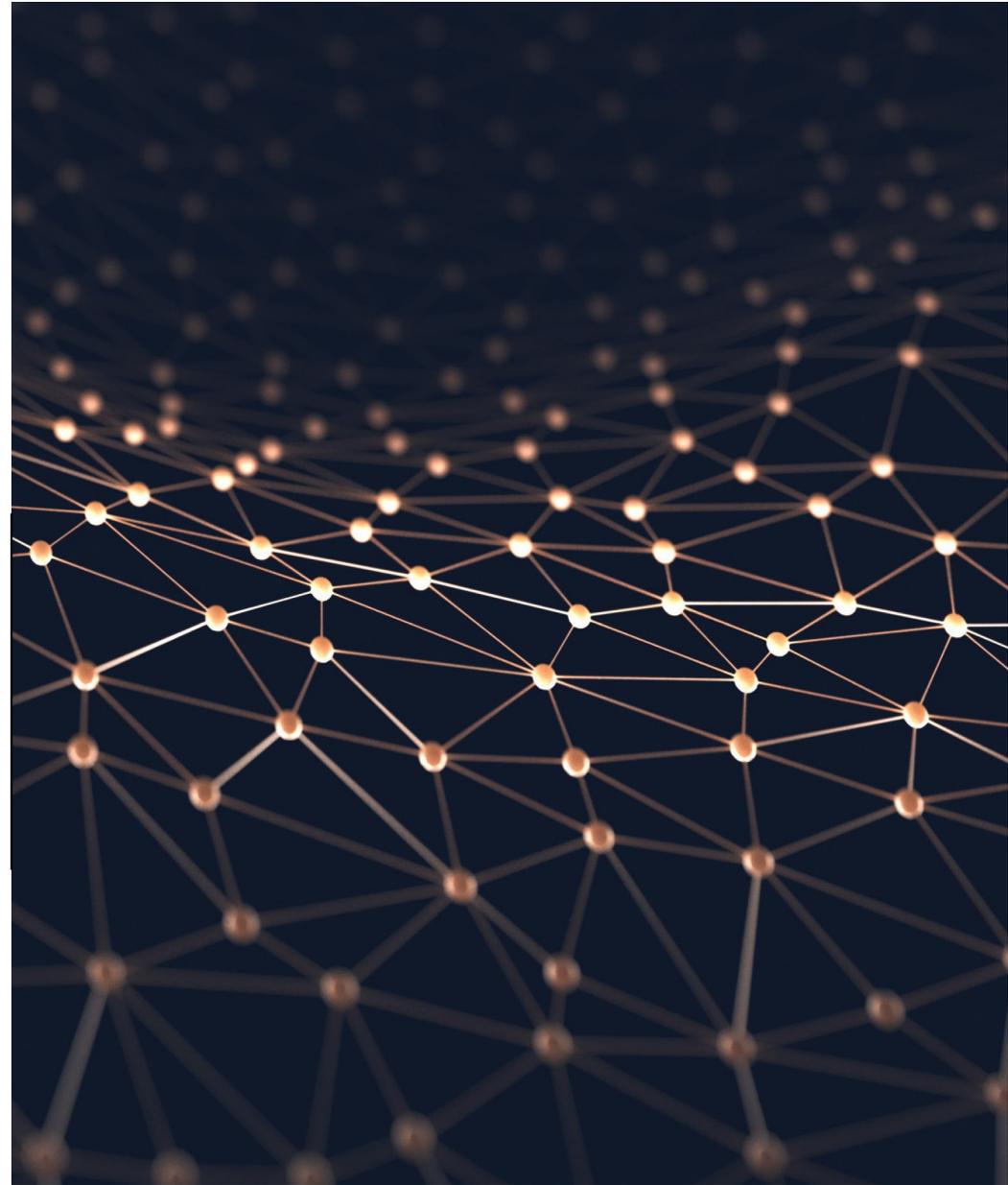
- Facilitate routine linkage of CQRs and administrative data
  - Meets legal and ethical requirements
  - Meets and reflects community expectations
- 

# Doctrinal Analysis



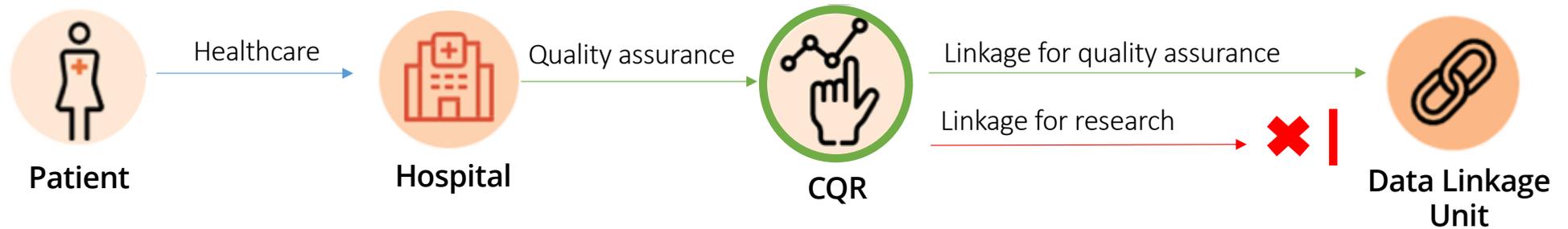
## Key Findings

- Consent
- Jurisdiction
- Purpose



# Privacy

## Waiver of Consent – *Privacy Act 1988* (Cth)



If:

(a) the APP entity is an organisation; and

(b) **subsection 16B(2) applied in relation to the collection** of the personal information by the entity;

the entity must take such steps as are reasonable in the circumstances to ensure that **the information is de-identified** before the entity discloses it in accordance with subclause **6.1** or **6.2**.



## Public Health Legislation - Confidentiality and disclosure

- Jurisdictional differences
- What you can do with data depends on the disclosure 'pathway'
- Limitations on further disclosure and re-identification



## Public Health Legislation - Quality assurance provisions

- ✓ Clear authorising provisions for the collection of health information
  - χ Statutory criteria
  - χ Re-application requirements
  
- ✓ Protection from liability
  - χ Provisions regarding disclosure



# Semi-Structured Interviews

training  
waiver de-identification siloes  
feed back complexity identifiers datasets  
PROMs time **research** registry function  
database jurisdiction **governance** national  
delays funding **ethics** streamline cost  
approvals consent **linkage** technical processes  
bespoke enduring quality assurance  
legal privacy data quality collection  
agreements custodians PREMs  
model hospitals SLK

✓ Clinical Quality  
Registries

✓ Administrative data  
custodians

✓ Ethics review bodies

✓ Data linkage units

# What next?

---

## Project pathway

- Co-Design Workshop

## Project Output

- 'Linkage' Framework & Guidance Materials



"After this nondisclosure agreement we also need you to sign this disclosure disagreement."

Anderson, M. Secrecy Cartoon#9076.  
[Illustration] <https://andertoons.com>.



# Acknowledgements

---

Dr Felicity Flack, Senior Manager, Strategy and Services, Population Health Research Network

Dr Carolyn Adams, Honorary Senior Lecturer, Macquarie University Law School

