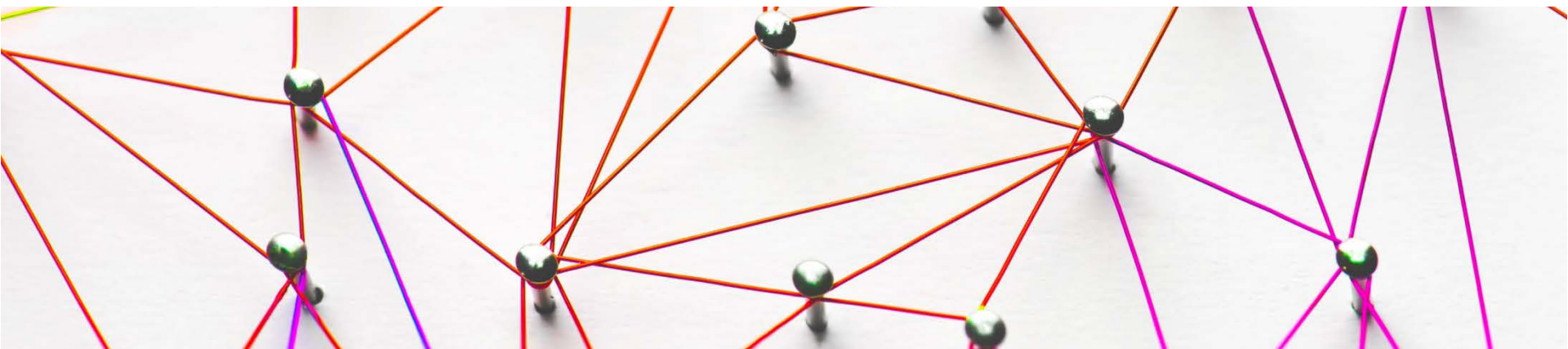




Is cumbersome governance killing research? The health data linkage perspective



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Data linkage/integration

- Combines information about an individual entity
 - Within and/or across multiple data sources
- Undertaken by accredited integrating authorities
- Designed to protect privacy and confidentiality
 - Individual identifiers not released
- Many additional safeguards
 - Increasingly data housed and analysed in data 'safe havens'



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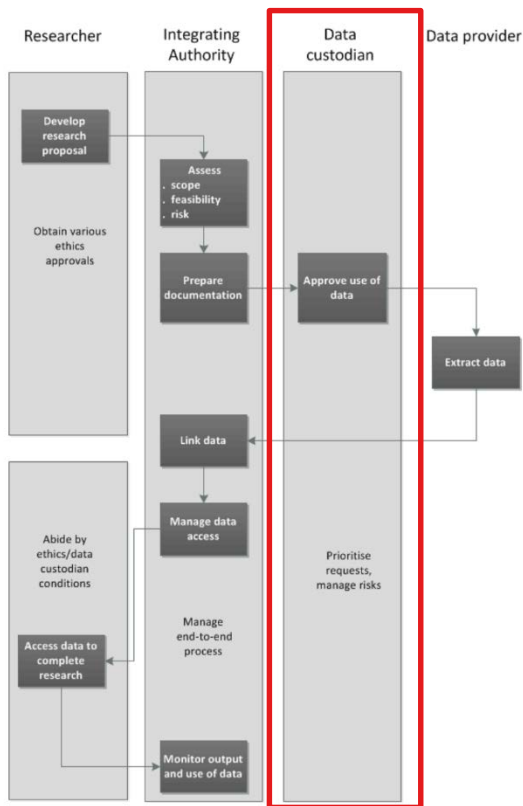


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'Five Safes' Principles



Overview of a typical data integration project



- Governance is role of data custodian
- Approve use of data
- Prioritise requests
- Manage risks
- *‘Data custodians are the most powerful players in data linkage research’*
- *‘They can make or break a project’*
- *‘I only have a year left on my grant.....’*

<https://www.aihw.gov.au/our-services/data-linkage/how-to-link-data>



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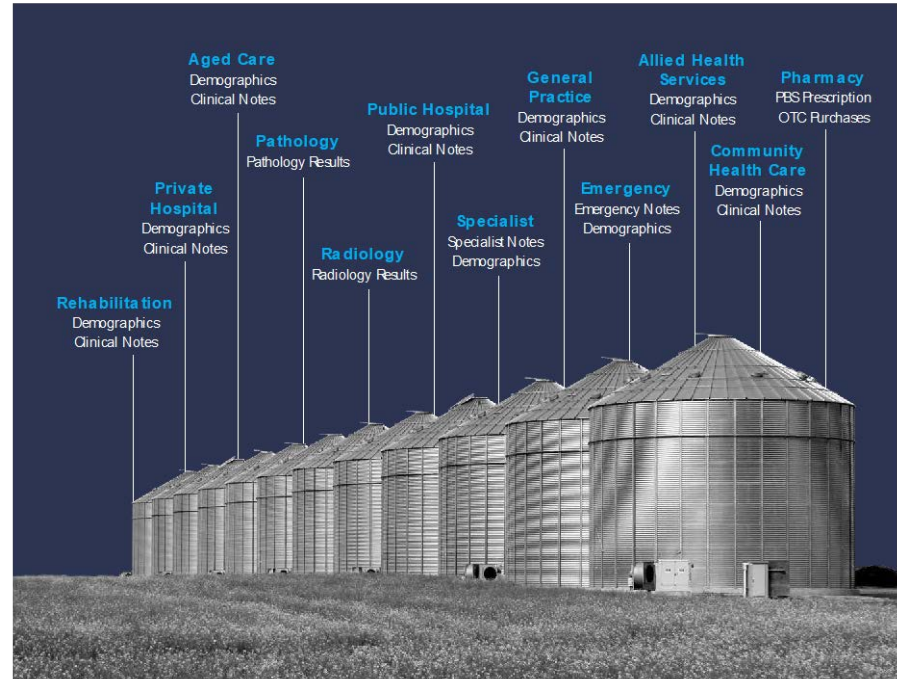
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Access denied - Australia's lost opportunities

'Australia stands out among other developed countries as one where health information is poorly used'

OECD 2015

Data is siloed.....
ethics is siloed, governance is siloed



<https://flyingblind.cmcr.com>



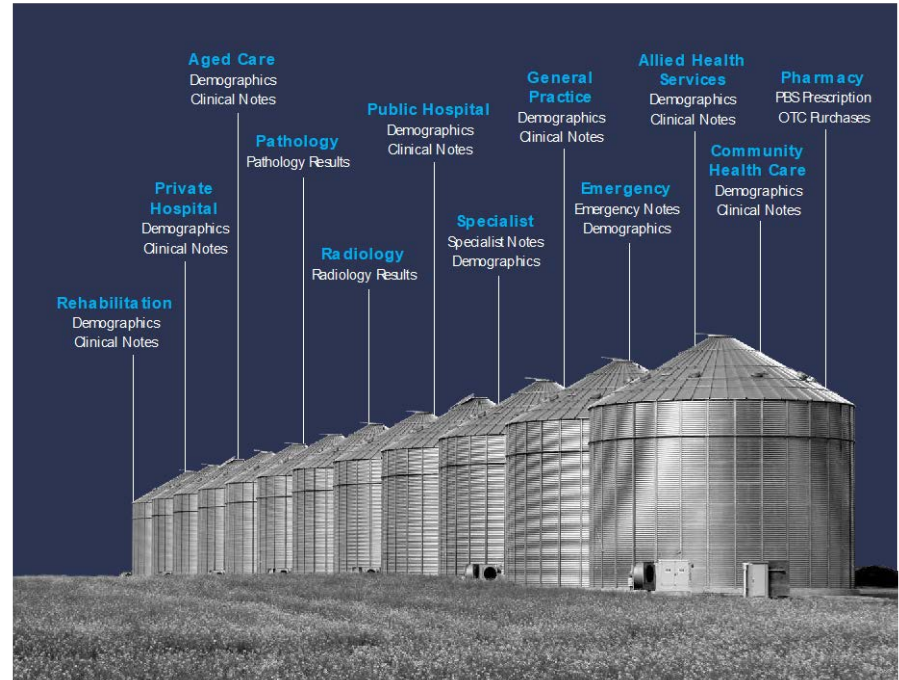
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Access denied - Australia's lost opportunities

- Strong governance pivotal
- Governance processes and decisions lack transparency
 - System relies heavily on oral histories
- Data custodians manage risk for their collection/s
 - Lack an overall system perspective
 - Limited consideration of 'knock on' effects of decisions
- Significant heterogeneity in 'back end' processes and requirements
- Dependent on person in role



<https://flyingblind.cmcr.com>



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Major reform underway.....



New data sharing and release arrangements

Led by the Minister Assisting the Prime Minister for Digital Transformation

Improve Australia's current data system

Address existing barriers, such as lack of standardised and transparent approaches to data sharing and release, and unnecessarily complex data access processes



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Addressing barriers.....

‘Move from a system based on risk aversion and avoidance, to one....., treating data as an asset and not a threat’

‘Adding more ad hoc adjustments to existing structures and legislation will not suffice’

- Reform should be underpinned by:
 - Whole-of-system perspective
 - Equity of access
 - Increased efficiency and waste reduction (while maintaining protections)
 - Improved transparency, education, communication and accountability
 - Considerations around scalability
- Manage expectations

Increasing data use does not necessarily increase risk

The Implant Files reveal how Australians were used as guinea pigs in medical device trial

Background Briefing By Alison Branley, Mario Christodoulou, Sophie Scott and Alex Mann

Updated yesterday at 6:14pm



PHOTO: Mr Neszpor feels like he's been used as a guinea pig in the trial of the shoulder device. (ABC News: Tom Hancock)

As a soldier, Wolfgang Neszpor spent a decade serving his country. But he never expected his most serious injury to come when he was safely back home in Brisbane.

RELATED STORY: This woman's implanted medical device came loose and started flipping over inside her



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