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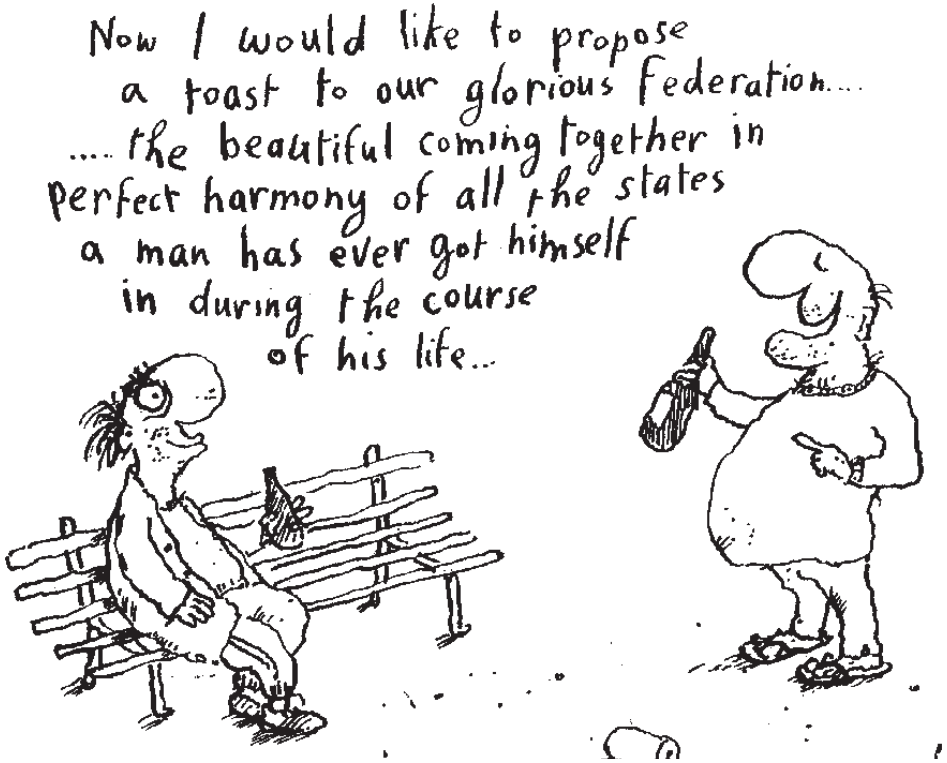
Cross-Jurisdictional Linkage – Enabling research at the national level

A/Prof James Boyd & A/Prof Anna Ferrante
PHRN Centre for Data Linkage

What is Cross-Jurisdictional Data Linkage?

Bringing together records from different systems *across states/territories (or Commonwealth)* related to the same individual (or 'entity')

1901-2001



Why do cross-jurisdictional data linkage?

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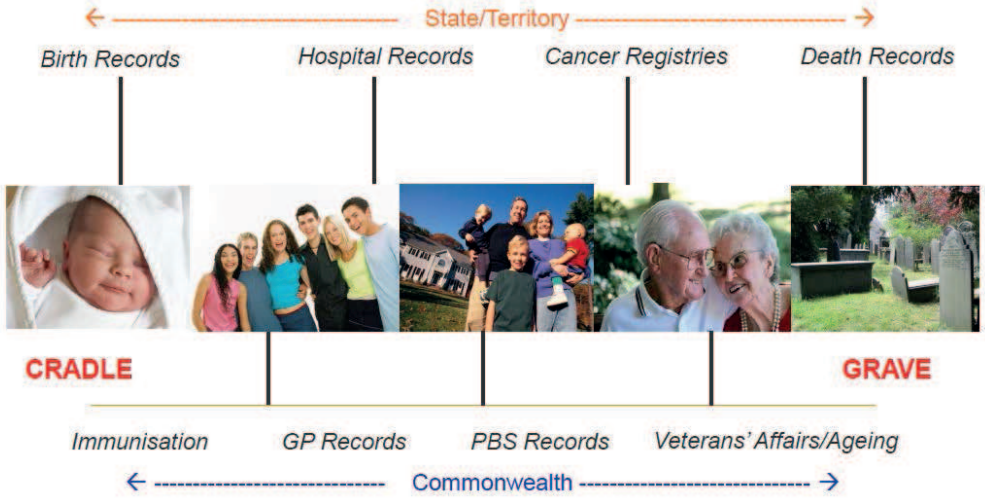
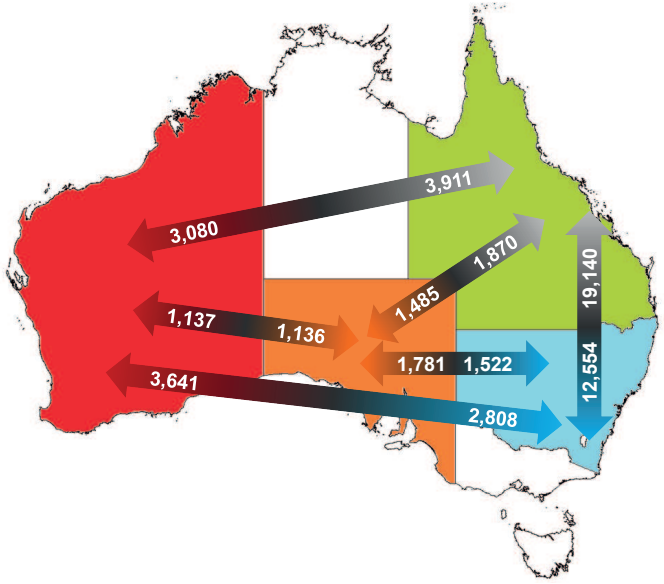
Complete patient pathways, care and outcomes



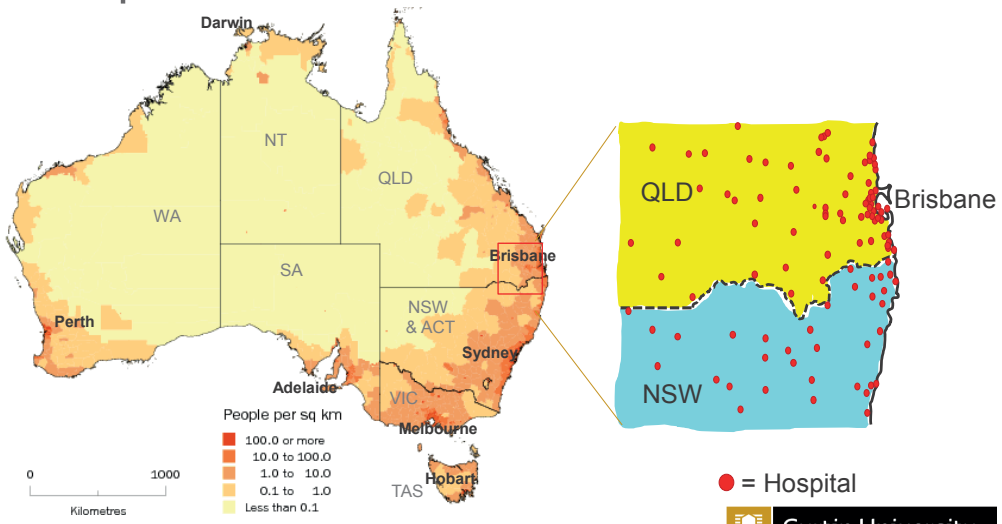
Longitudinal studies & population mobility



Over time (5yrs), people move

Source: PHRN POC1

Cross-border service use



Source: Australian Bureau of Statistics

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Rare Conditions & Outcomes

RD Category Prevalence

RD Category [1]	
RA	Infectious and parasitic diseases
RB	Neoplasms
RC	**Endocrine, nutritional and metabolic diseases, and immun**
RD	**Diseases of the blood and blood-forming organs**
RF	**Diseases of the nervous system and sense organs**
RG	Diseases of the circulatory system
RI	Diseases of the digestive system
RJ	Diseases of the genitourinary system
RL	Diseases of the skin and subcutaneous tissue
RM	Diseases of the musculoskeletal system and connective tissue
RN	Congenital ar
RP	Certain condi
RQ	Symptoms, sig

[1] International Classifica
[2] Census 2011 – http://d

RARE DISEASE AND ORPHAN DRUG R

Rare Disease			
RF0100	Amyotrophic lateral scleros		5,20
RC0210	Behcet disease		4,00
RF0180	Chronic inflammatory demyeli	5,79	3,70
RN0680	Turner syndrome	5,10	20,00

[1] Orphanet Report Series - Rare Diseases Colle ...une 2013, Number 1
[2] Census 2011 – http://dati.istat.it

Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2014; 15: 1–8

ORIGINAL ARTICLE

Record linkage between hospital discharges and mortality registries for motor neuron disease case ascertainment for the Spanish National Rare Diseases Registry

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Abstract

Our objective was to analyse the coverage of hospital discharge data and the mortality registry (MR) of La Rioja to ascertain motor neuron disease (MND) cases to be included in the Spanish National Rare Diseases Registry. MND cases that occurred in La Rioja during the period 1996–2011 were selected from hospital discharge data and the MR by mo of the International Classification of Diseases. Review of the medical histories was carried out to confirm the cause death reported. Characteristics of the population with MND were analysed. A total of 133 patients with MND detected in La Rioja during the period 1996–2011; 30.1% were only recorded in the hospital discharges data, only in the MR, and 57.9% were recorded by both databases. Medical records revealed a misscoding of patients w been diagnosed with progressive supranuclear palsy but were recorded in the MR with an MND code. In co the hospital discharges data and the MR appear to be complementary and are valuable databases for the Spanish Rare Diseases Registry when MNDs are properly codified. Nevertheless, it would be advisable to corre validity of the MR as data source since the miscoding of progressive supranuclear palsy has been corrected

Key words: *Rare disease, surveillance, administrative database, International Classification of Diseases*

Why do cross-jurisdictional data linkage?

Increase statistical power for research on rare conditions or outcomes

Accurate data for longitudinal studies

People move or die interstate, seasonal or out of state workers (FIFO)

Ascertain complete patient pathways, care and outcomes (welcome to Federation)

Assess cross-border service utilisation

Evaluate state-based variations in hospital and health care

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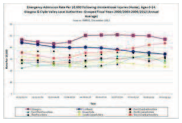
Examples of cross-jurisdictional studies

- Proof of Concept 1
- Proof of Concept 2
- Proof of Concept 3
- Proof of Concept 4

http://www.phrn.org.au/projects/concluded-projects/

Proof of Concept 1

- **In-hospital and post-discharge mortality:** learning about quality of care using data linkages from four Australian states
- XJ linkage of hospital records & death registrations, WA, SA, NSW & Qld
- Outcomes: Refined SMRs, cross-border flows, completeness of patient pathways




POC#1: Data cleaning by state

Excluded episodes of care (hospital records)	NSW	WA	QLD	SA	Total excluded
Potential funding duplicate records – one kept	31,345	0	9,358	964	20,903
Missing age at admission	842	0	0	0	842
Missing sex or intersex	199	3	6	3	211
Missing principal diagnosis	28,738	0	0	0	28,738
Newborn[3], boarder, organ procurement care types	604,128	36,473	427,795	22,042	1,090,438
Non-hospital facility (rehab, nursing, hospices)	149,416	0	13,447	1,879	164,742
Non-medical hospital encounter (Z76)	1,899	4,137	1,496	760	8,292
Cancelled procedures (Z53)	1,609	0	35	0	1,644
Missing, unknown or overseas postcodes	84,888	8,412	30,788	3,267	127,355
Separation date < admission date or missing	125	0	0	0	125
Total excluded	**903,189**	**49,025**	**482,925**	**28,915**	**1,443,290**

POC#1: Coding variation between states

	NSW		WA		QLD		SA	
	N	%	N	%	N	%	N	%
Day case chemotherapy (Z51.1)								
Public hospital	26,784	11.5	150,826	53.5	180,891	36.0	63,606	100
Private hospital	206,693	88.5	131,011	46.5	321,812	64.0	-	
Day case renal dialysis (Z49.1)								
Elective	1,606,258	91.5	0	0	57,316	4.7	0	0
Emergency	12,581	0.7	0	0	290	0.02	0	0
Not assigned	136,494	7.8	729,104	100	1,159,719	95.3	313,774	100.0
Single delivery (O80)								
Elective	25,798	30.4	0	0.0	1,866	2.7	0	0.0
Emergency	2,155	2.5	0	0.0	6,472	9.5	0	0.0
Not assigned	57,029	67.1	23,983	100.0	59,521	87.7	11,205	100.0
ED deaths recorded as in-patient	Yes		No		No		No	

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Other PoCs

- **Proof of Concept 2** = burden of injury, linkage of hospital, ED & death records, multi-state (NSW, SA, Qld)

- **Proof of Concept 3** = perinatal risk factors & developmental outcomes, multi-state linkage & AEDC

- **Proof of Concept 4** = vaccination update, effectiveness and burden of infection, linkage of NSW & WA (hospital, ED, perinatal) to ACIR.

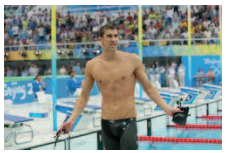
Examples of other cross-jurisdictional studies

- Marfan disease (rare disease)
- Epilepsy study (registry)
- Continuity of Care (popn, $ NHMRC 2015)
- SHIP study (cohort, $ NHMRC 2016)

Marfan syndrome

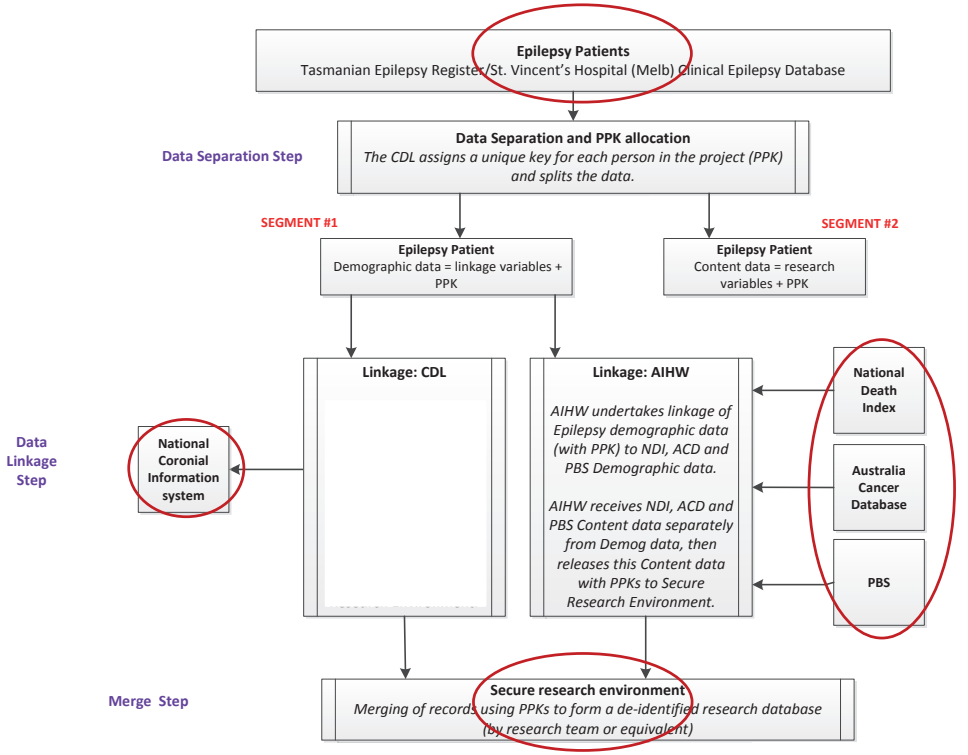
- Describe epidemiology of this rare condition
- Estimate incidence & prevalence
- Examine hospital use, comorbidities, mortality
- Multi-state: WA, NSW, SA
- Cohort = ICD9 759.82; ICD10 Q87.4
- Linkage: Hospital admissions & Death registrations
- CIs = Brameld et al (Curtin University)





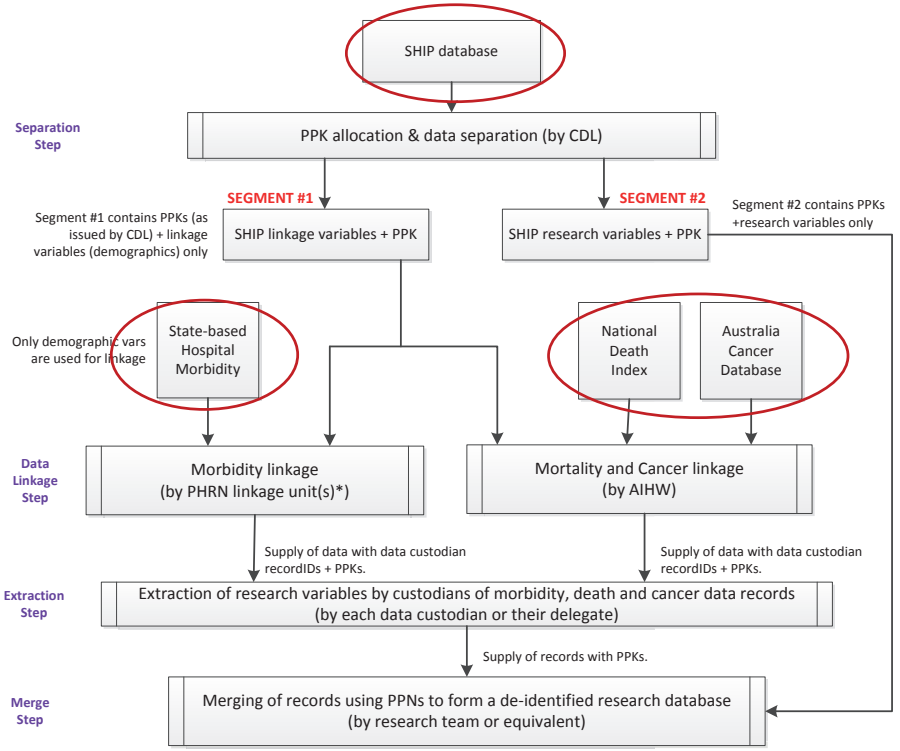

Epilepsy study

- Follow-up study of epilepsy patients in 2 state-based Epilepsy Registers
- Examine risk for mortality
- Explore patterns of AED use, co-morbidities
- Examine context of mortality (qualitatitive)
- CIs = D'Souza et al (UniMelb)



SHIP study

- Follow-up study of “SHIP” participants
- **SHIP = large, national survey of people with psychotic illness**
- Examine risk for mortality & morbidity
- Estimate economic & social costs
- NHMRC, 3 year project
- CIs = Morgan et al (UWA)



Continuity of Care

- Evaluate effects of coordinated health services
- Role of primary healthcare
- Assess patterns of care (primary & secondary)
- Outcomes for chronic / complex conditions
- Potentially preventable hospitalisations
- System costs
- NHMRC, 4 year project (2015-2018)
- Cis = Moorin et al (Curtin University)

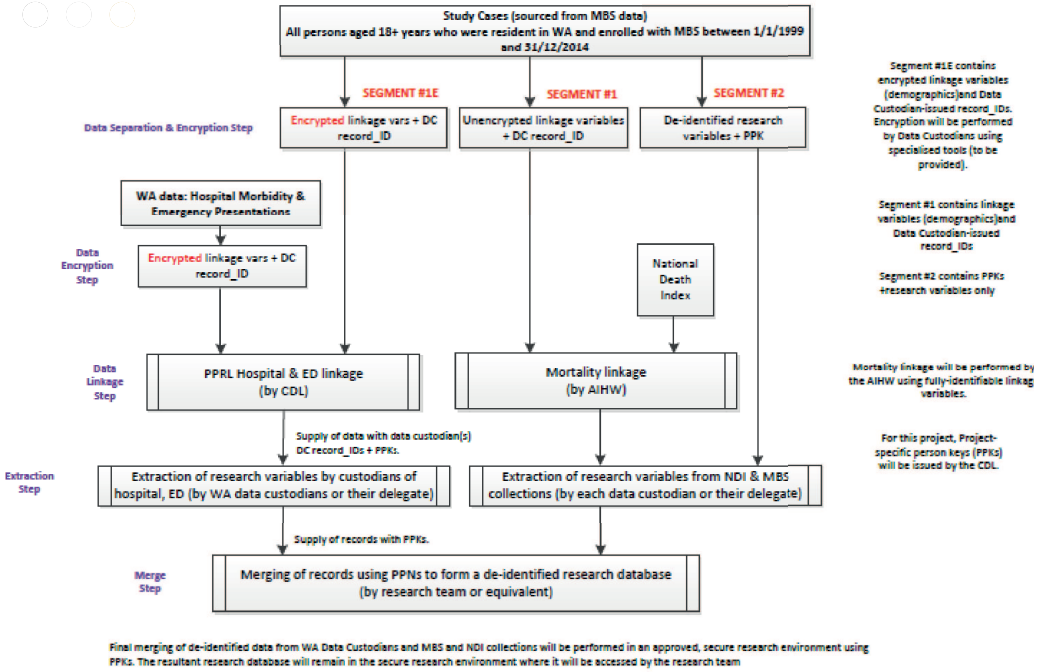
Continuity of Care

- Project Design & Data:
  - Design: Whole of population, longitudinal
  - Cohort: identified using Medicare enrolments
  - Outcomes: from State (WA) & Commonwealth data
- Datasets collections required:
  - Medicare Benefit Scheme (MBS)
  - Hospital Morbidity (WA)
  - Emergency Department (WA)
  - Deaths (WA)

Progress so far…

- Approval processes:
  - Curtin ethics - approved
  - AIHW Ethics - approved
  - WA Data Application - completed
  - Commonwealth Risk assessment - nearly there
- Data linkage requirements:
  - Combine State & Commonwealth data
  - Navigate Legal and Regulatory Barriers
  - State/AIHW data disclosure requirements

Proposed Project Data Flows – Creation of Project-specific person keys (PPKs) and multi-jurisdictional data linkage



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What are the challenges of cross-jurisdictional DL studies?

Challenges

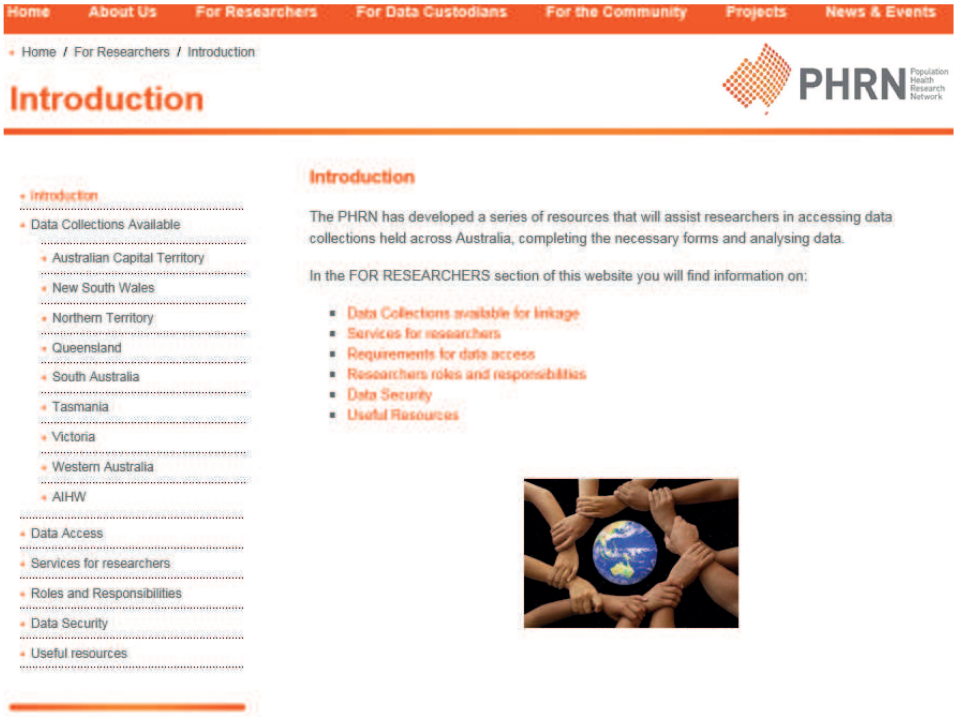
- **Assessing feasibility** – data availability, quality, what's possible & what's not?
- **Approvals & application processes** – how many, how long?

- Wait times and cost
- Analysis – larger datasets, coding variations, comparability

Where do you start ?

Resources

- **PHRN Website** (phrn.org.au)
  - General information
  - Processes – Ethics & Data Custodian approvals
  - Available datasets
  - Metadata links
- PHRN **On-line Application system** (https://oas.phrn.org.au)
- DLU Websites
- Human help (email or call with queries)
  - cdl@curtin.edu.au vdl@dhhs.vic.gov.au phrn@uwa.edu.au
- SUFEX - transferring data securely
- SURE – analysing data securely



What datasets are available?

Check the PHRN Website
phrn.org.au & DLU websites

Data Collection	Avail Date
Commonwealth	
ACD	1982+
MBS	2012
PBS	2012
NDI	1980
ACIR	1996
Other National	
AEDC	2009,2012, 2015
Victoria	
ED	2000
Admitted patients	1993
Cancer registry	2003
Deaths	1993
WA	
Births	1982
Perinatal	1980
Hospital	1970
ED	2002
Cancer registry	1982
Death	1969
Mental Health	1966

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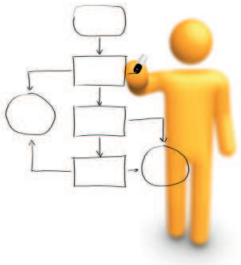
Approvals processes



- At a minimum, institutional HREC
- If State-level: Data Custodian (DoH++) & HREC
- If Commonwealth, then AIHW EC & Commonwealth custodian approval(s)
- OAS Stages: RFQ, EoI, Full data application, HREC

Advice:

For HREC, use NEAF if possible (reusable). Check reciprocal arrangements.

Consent involved? Check wording with Cwth DHS

Complexity = longer timeframes & higher cost

Complexity – new linkage? Cases & controls? No & type of datasets?

Q. Can I get access to Commonwealth data?

A. Which dataset? Time period? Linkage involved? Consented or unconsented? High risk project?

Q. What is SURE and do I have to use it?

A. Requirement for 'high risk' linkage projects involving Commonwealth data. Costs vary.

Q. How do I use SUFEX?

A. Register via support@sufex.org.au. Free (for now).

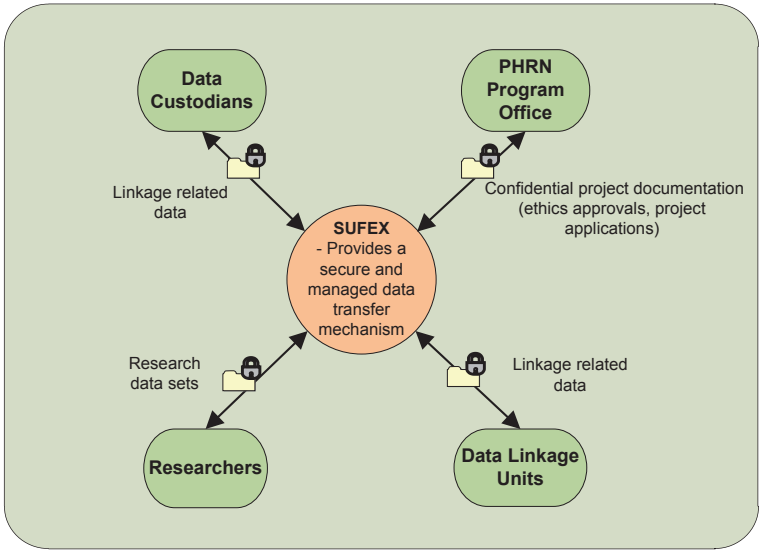
Any other questions? Please ask ☺

SUFEX Secure Unified File Exchange

What is SUFEX?

- A secure file transfer service for the PHRN and its stakeholders
- Uses secure online software to send and receive files from anywhere at anytime
- Easy to use, web-based
- It is *not* a file storage solution
- The service is provided (free!) but registration required
- Hosted and maintained by the CDL

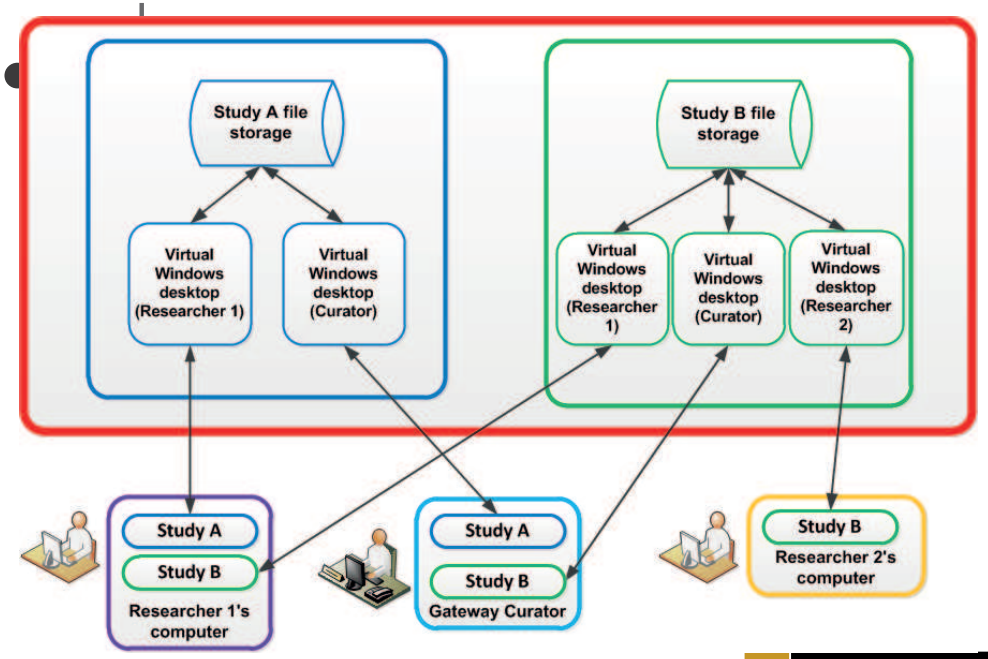
SUFEX Secure Unified File Exchange



SURE

Secure Unified
Research Environment

- a secure remote computing environment for research using linked health data
- operated by the Sax Institute
- SURE replaces current researcher computing environment only



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SURE Secure Unified Research Environment

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access to SURE

- remote access to SURE is strongly authenticated
- additional means of authentication in addition to a username and secret password
  - one-time-use access code provided by a hardware token (Yubikey) or smartphone

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SURE Secure Unified Research Environment

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Challenges aside…

Notwithstanding the challenges, working with linked data can be…

sweet, rich and delicious…

…just like chocolate!