



Attachment 7: Cross-Jurisdictional Linked Data Projects, 2012-2015

Year submitted	Title	Status	Comments
2015	Quantifying the burden of systemic sclerosis in Australia: from data linkages to patient-reported outcomes	Pending Data Custodian approval in progress	Cohort provided for linkage by researcher.
2015	LungScreen WA Project	Pending participant recruitment	To come back for full application review in ~2018/2019 when participants have been recruited and data is ready for linkage.
2015	Evaluating the effect of providing tailored patient education for older people at hospital discharge in addition to usual care on rates of falls after hospital discharge compared to providing a social intervention in addition to usual care – a randomised controlled trial	Pending DoH HREC approval	Cohort provided for linkage by researcher.
2015	Enhancing the accuracy of heart disease risk assessment in Indigenous Australians. Short title: Cardiovascular Risk in Indigenous People (CRISP study)	Pending data release (currently in progress in DLB)	Cohort provided for linkage by researcher.
2015	Parenthood in patients receiving dialysis or kidney transplantation: a national study of perinatal risks and outcomes through population record linkage	Pending completion of draft review process	Cohort for linkage provided by data custodian.



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2015	Does continuity of primary care reduce demand on emergency department presentations and hospital admissions?	Pending completion of draft review process	Requesting DoH identifying data in a privacy preserved state for linkage at the Centre for Data Linkage. Project originally requested patient identifiers for linkage, which was stalled due to legislative impediments. Project now trialling privacy preserving measures applied to demographic data to be used for linkage. Feasibility review recently resumed.
2015	Re-evaluation of link between inter-pregnancy interval and adverse birth outcomes: Retrospective cohort study matching two intervals per mother	Pending completion of draft review process	Jurisdictional data is being pooled—no cross-jurisdictional linkage <i>per se</i> .
2015	Epidemiological profile of Marfan Syndrome	Withdrawn	Requested DoH identifying data for cross-jurisdictional linkage. The DoH was unable to support the request for release of identifiers for linkage due to legislative impediments.
2015	Recent changes in IVF clinical practice: data linkage to investigate their impact on fetal growth, birth defects and cerebral palsy.	Pending data agreement between WA Registry of Births, Deaths & Marriages and Australian Institute of Health & Welfare	Identifiers from WA Birth and Death records for linkage with Commonwealth data.
2015	Improving access to primary care for Aboriginal babies in Western Australia: the 'STORK' population based study	Pending Data Custodian approval in progress	Cohort provided for linkage by researcher.



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2015	Incidence and burden of childhood injury in Australia	Completed	
2015	Living with Acute Coronary Syndrome	Pending DoH HREC approval	National cohort provided for linkage.
2015	An empirical framework for assessing mortality and morbidity in people with psychotic illness: 7-year follow-up and 10-year retrospective analysis of 2,075 Survey of High Impact Psychosis (SHIP) participants using linked mortality and health registers	Pending updated application from researcher	Waiting for response from researcher since August 2015.
2015	South Australia and Northern Territory Stroke Study (initial phase) (SAiNTSS1)	Pending completion of linkage work (in progress)	Jurisdictional data is being pooled—no cross-jurisdictional linkage <i>per se</i> .
2015	Risk of a subsequent primary ovarian cancer in breast cancer patients: a population-based study in Western Australia	Pending completion of draft review process	Cohort provided for linkage by researcher.
2015	Linking data from three national cancer screening programs	Pending completion of draft review process	Waiting since December 2015 for clarification on services required by DLB.
2014	Population-level relevance of risk factors for cancer	Withdrawn	Will seek alternative data sources.
2014	The cost-effectiveness of sustaining tenancies of formerly homeless clients with high needs	Completed	Cohort provided for linkage by researcher.
2014	Investigating vaccine safety via cross-jurisdictional data linkage of the Australian Childhood Immunisation Register with hospital morbidity data (Western Australia component)	Withdrawn	DoH identifying data identifiers for linkage The DoH was unable to support the request for release of identifiers for linkage due to legislative impediments.



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2014	A cohort study to investigate the association between maternal and childhood immunisations	Withdrawn	Superseded by <i>Survey of antenatal influenza vaccination uptake in 2014, and the association between maternal antenatal influenza vaccination uptake and childhood immunisation status at 2, 4, 6 and 12 months.</i>
2014	Linked Perinatal, Birth, Death Data Set project	Completed	Identifiers from Birth Registry for linkage Approved by the Registrar General for release of Birth identifiers for linkage. DoH identifiers not approved for release due to legislative impediments.
2014	Measuring rates and correlates of breast cancer screening, diagnosis and treatment using Western Australian population linkage	Withdrawn	Researcher decided to revise and resubmit at a later date.
2014	Patterns of care in adolescents and young adults with cancer	Withdrawn	Researcher decided to obtain data directly from the hospitals (not via DoH).
2014	Stroke123 sub-study: establishing integrated data for stroke to enable comprehensive monitoring of care and patient outcomes to provide evidence for clinical practice improvement	Pending completion of linkage work (in progress)	Cohort provided for linkage by researchers.
2013	Pharmacotherapy for smoking cessation during pregnancy and the inter-pregnancy period	Completed	
2013	EXTending the ANZDATA Registry by linking to administrative datasets (EXTANZ).	Completed	Cohort provided for linkage by researchers.



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2013	Developmental trajectories in Australia: perinatal outcomes and child development (risk and protective factors).	Closed due to inactivity	Requested identifying data from DoH as well as other agencies. Draft application has been inactive for almost a year.
2013	An international collaboration for autism registry epidemiology: multinational investigations of autism risk factors and trends (MINERvA)	Completed	International data is being pooled—no cross-jurisdictional linkage <i>per se</i> .
2013	SMARTHEART: A community based heart failure service	Pending completion of linkage work (in progress)	Cohort provided for linkage by researchers.
2012	The utilisation of medications during pregnancy and the associated health outcomes	Rejected by DoH HREC	Draft application resubmitted as different project which was approved and delivered.
2012	The burden and cost of injury attributable health care use and mortality in Australia	Closed due to inactivity	DoH identifying data requested for cross-jurisdictional linkage. Legal advice on release of identifiers for linkage sought. Due to lack of response from researcher for over 12 months, project was discontinued.
2012	Linkage of the Australian Childhood Immunisation Register (ACIR) and State-based registers to evaluate and inform Australia's immunisation program	Completed	Requested identifiers from Birth Registrations for linkage.

Abbreviations:

DoH: Department of Health

DoH HREC: Department of Health Human Research Ethics Committee

Note: No new cross-jurisdictional linkage projects were submitted in 2011.



Government of **Western Australia**
Department of **Health**