



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

Department of Health Western Australia Human Research Ethics Committee

Project Summaries for Approved Proposals

January to March 2020 Quarter

Project summaries for proposals approved by the Department of Health Human Research Ethics Committee – January to March 2020 quarter.

The material contained in this document is made available to assist researchers, institutions and the general public in searching for projects that have ethics approval from the Department of Health Human Research Ethics Committee (DOH HREC). It contains lay description/summaries of projects approved in the January to March 2020 quarter.

Project Title	Using total population data to produce policy-relevant evidence to increase access to services for Aboriginal children with intellectual disability / autism spectrum disorder in Western Australia		
Principal Investigator	Dr Alison Gibberd		
Institution	The University of Melbourne		
Start Date	19 February 2020	Finish Date	19 February 2023

Aboriginal children with intellectual disability and/or autism spectrum disorder ('developmental disability') in Western Australia are less likely to access disability services early than non-Aboriginal children. However, it is not known how much this varies by region and across families. The reasons children do not access services in early childhood are also poorly understood; they may include delays in diagnosis, barriers to accessing services and inappropriate services.

Aboriginal families affected by developmental disability (among the children or parents) have high levels of contact with the child protection system as Aboriginal children, children with developmental disability and children with parents with intellectual disability are all over-represented in the system. The experiences of these families are not known, nor is it known if receipt of disability services reduces the likelihood of child removal.

The aims of this study are to use linked, population-based data to:

1. identify regions of Western Australia where health services are making early diagnoses and children are accessing disability services in early childhood;
2. identify characteristics of children and families where children are diagnosed early and receive services early (e.g. parental age and level of contact with healthcare services). This will inform pathways to increase early diagnosis and identify possible barriers to accessing services; and
3. examine the relationship between developmental disability and the child protection system and how this varies with access to disability services and other strengths and vulnerabilities within the family.

Project Title	Australian hepatitis B and hepatitis C duplicate notifications linkage project		
Principal Investigator	Professor Benjamin Cowie		
Institution	WHO Collaborating Centre for Viral Hepatitis, Doherty Institute		
Start Date	28 January 2020	Finish Date	28 January 2023

Nearly two percent of Australians are currently living with hepatitis B or hepatitis C infection. These infections can cause severe consequences such as liver disease and liver cancer if left unmanaged. These undesirable outcomes are becoming increasingly common despite often being preventable through access to effective care and treatment. In order to understand how effectively Australia is improving access to care for those who have hepatitis B and hepatitis C, accurate estimates of the number of people who are currently living with these infections and the number who have been diagnosed, are needed. Data regarding the number of people who have ever tested positive for hepatitis B and hepatitis C ('notifications') are reported to each state and territory health department by testing laboratories in their jurisdiction whenever a test is positive. These individual state and territory numbers are combined to provide national numbers, however there is the potential for people to be counted more than once if they are tested and diagnosed in more than one jurisdiction.

This study will collect and link together all notified diagnoses of hepatitis B and hepatitis C across Australia, to find out how many individuals have been notified with infection, what has happened over time, and what factors make people more likely to have a duplicate notification in another state. This information will then be used to more accurately estimate the proportion who have been diagnosed, and the uptake of care and treatment to measure Australia's progress towards improving the response to hepatitis B and hepatitis C. This linkage dataset will be supplemented with data regarding deaths recorded in the National Death Index, in order to provide further detail regarding the number of currently existing cases of hepatitis B and hepatitis C, after the exclusion of those who have died. The dataset will additionally be linked to the Medicare Enrolment File to help better identify duplicates.

Project Title	Indigenous Child Removals Western Australia		
Principal Investigator	Professor Sandra Eades		
Institution	The University of Melbourne		
Start Date	14 February 2020	Finish Date	20 February 2023
<p>Up to one in ten Australian Aboriginal children are in foster, kinship or residential care on any one night; 10 times the rates of non-Aboriginal children (up to 17 times in Western Australia). Australian Aboriginal children are also more likely to be reported, investigated, substantiated or have evident harm than non-Aboriginal children in the first five years of life. Importantly, one report found that the proportion of investigated notifications was the same for Aboriginal and non-Aboriginal children, however the substantiation rate was higher among Aboriginal children (up to 11 times higher in WA as reported in 2015-2016). Overall, Aboriginal children and youth in WA had increased risk of substantiated notifications for all categories of maltreatment (emotional, neglect, physical and sexual) with the risk for neglect being 17 times higher.</p> <p>Data suggest the rates for Aboriginal children are increasing and that Aboriginal children are entering out-of-home care at earlier ages and staying for longer durations. Of concern, the number of Aboriginal children placed with kinship carers is declining.</p> <p>The overall aims of the project are to identify factors that will help reduce the number of Aboriginal children going into out-of-home care and ways to better support families at risk of having children removed, children in care and kinship carers. There have been no studies that have examined risk factors for out-of-home care for Aboriginal children beyond an index of social disadvantage and maternal age. Hence, another major aim of the project is to identify the demographic, social and health predictors of out-of-home care among Aboriginal children in WA.</p>			

Project Title	Anaphylaxis characteristics and epidemiology in Western Australia (ACE-WA) Study.		
Principal Investigator	Dr Sandra Salter		
Institution	The University of Western Australia		
Start Date	9 March 2020	Finish Date	9 March 2023

Anaphylaxis is a severe and potentially life-threatening systemic allergic reaction. Anaphylaxis is an important contemporary public health problem in Australia, with the highest rates of food allergy in the world and some of the highest rates of food anaphylaxis observed in this population. The Anaphylaxis characteristics and epidemiology in Western Australia (ACE-WA) project is a linked data cohort study that aims to determine the current population epidemiology of anaphylaxis in Western Australia (WA) and how it has changed over time.

This study will identify an anaphylaxis cohort (ACE-WA Cohort) from 1980 onwards, using ambulance; emergency department; hospital inpatient and deaths, linked datasets. This cohort will be used to measure incidence, prevalence and recurrence of anaphylaxis and investigate the impact of age, gender, cause and dataset on anaphylaxis event rates. Patient care pathways, from prehospital ambulance care through to the emergency and in-hospital setting for anaphylaxis events will also be explored.

Linked records for the anaphylaxis cohort, will be used to build a clinical picture of the health conditions that may be precursors to the development of anaphylaxis as well as comorbidities that may be associated with anaphylaxis outcomes, particularly severe and recurrent reactions and death. This research project hypothesises that anaphylaxis is dramatically increasing in the Western Australian population. It is expected that the study will provide vital information about the current burden, characteristics and healthcare utilisation for anaphylaxis in WA. The use of linked health data will provide the most comprehensive epidemiological estimates to be obtained to date and provide insight into the patient care journey, which are essential for better planning and funding of anaphylaxis health services.

The use of linked data to identify comorbidities for anaphylaxis patients will provide important information about the risk of future anaphylaxis events and will build a better clinical picture of this condition in the WA population.

Project Title	Impact of initiatives aimed at increasing adolescent HPV vaccination coverage – an evaluation in Western Australia		
Principal Investigator	Associate Professor Linda Selvey		
Institution	School of Public Health		
Start Date	12 March 2020	Finish Date	12 March 2023
<p>Human papillomavirus vaccine (HPV vaccine) is a highly effective vaccine that prevents a number of cancers including cervical cancer as well as genital warts. The current vaccination schedule involves two doses of the vaccine for 12 to 13 year old children (in year 7) delivered 6 months apart. HPV vaccine coverage in Western Australia is high, but is lower among Aboriginal children and children of lower socio-economic status. In July 2019, WA Health undertook two initiatives to increase HPV vaccine coverage. The purpose of this research is to evaluate these initiatives from the perspective of their impact on HPV vaccination coverage and on staff workflow and resources.</p>			

Project Title	Estimating the incidence and cost of communicable illness in Western Australian travellers returning from Indonesia.		
Principal Investigator	Dr Paul Effler		
Institution	Department of Health		
Start Date	20 March 2020	Finish Date	20 March 2023
<p>Indonesia is a very popular holiday destination for Western Australians (WA). WA travellers now account for nearly half of the total Australian visitors to Indonesia, increasing more than five-fold between 2006 and 2018. There were over 472,000 departures from Perth to Indonesia in 2018, with nine flights, on average, every day. Notifiable diseases attributed to travel to Indonesia are reported to the WA Notifiable Infectious Diseases Database (WANIDD), a database managed and maintained by the Communicable Disease Control Directorate in WA Health.</p> <p>WANIDD incidence data regarding Indonesian travel was previously reported on an ad hoc basis through the now defunct Disease Watch publication. No updated data has been published through Disease Watch since 2013, and there has been no data published regarding the cost of Indonesian travel related illness.</p> <p>The main objective of this project is to determine the incidence of disease notifications attributed to travel to Indonesia from 2009 to 2018, with a particular focus on diseases of note, e.g. measles, dengue, chlamydia and bacterial gastroenteritis. A cost of illness analysis will be performed on the notification data to estimate the annual cost of notifiable illness in WA travellers to Indonesia.</p> <p>De-identified WANIDD data will be analysed to produce a descriptive analysis of disease incidence in WA travellers to Indonesia. Incidence data will subsequently be used to perform a cost of illness analysis. These analyses will help to inform future public health measures in our state.</p>			

Project Title	Age of diagnosis of congenital anomalies in Western Australia		
Principal Investigator	Dr Erin Kelty		
Institution	The University of Western Australia		
Start Date	20 March 2020	Finish Date	20 March 2023
<p>Advancements in the screening, detection and diagnosis of congenital anomalies have likely resulted in congenital anomalies being diagnosed at an earlier age. The aim of this project is to examine the age of diagnosis of congenital anomalies and examine how the age of diagnosis has changed since the implementation of the register in 1980. The study will examine records collected by the Western Australian Register of Developmental Anomalies. Records will be classified as having been diagnosed during pregnancy, the neonatal period (0 – 28 days following birth), infancy (29 – 365 days) or early childhood (1 – 6 years of age). Trends in the age of diagnosis will be examined by birth year for 1980 to 2014 using ordinal logistic regression.</p>			

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