Human Research Ethics Committee

Project Summaries for Approved Proposals

April to June 2016 Quarter

Project summaries for proposals approved by the Department of Health Human Research Ethics Committee – April to June 2016 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 available for the April to June 2016 quarter.

Project Title	The impact of a nurse-supported, community-based heart failure management service on self-management behaviour and psychosocial outcomes. [Short title: Nurse-supported heart failure management]		
Principal Investigator	A/Prof Andrew Maiorana		
Institution	Curtin University		
Start Date	1 March 2016	Finish Date	1 December 2017

Heart failure is a relatively common condition where cardiovascular disease leads to impaired pumping ability of the heart resulting in symptoms of fatigue and breathlessness, and high rates of recurrent hospital admissions. In April 2013, Curtin University commenced a nurse led clinic (the Clinic) to support people with heart failure (HF) manage their condition. The aim of the clinic was to improve the lives of heart failure patients and reduce hospital admissions by providing patients with community-based clinical support and regular examinations.

One objective of the overall project was to evaluate the effects of the Clinic on self-management behaviour, symptom recognition and quality of life in people with HF compared with patients with HF who haven't had access to the Clinic (comparison group). This study entitled, The impact of a community-based heart health service on self-management behaviour and psychosocial outcomes (the original study) was approved by the Royal Perth Hospital (RPH) (REG 13-171) and Curtin (HR12-2014) Ethics Committees. Analysis of this data has revealed that participants who attended the Clinic had better self-management strategies and quality of life. It is anticipated that this will translate to improved clinical outcomes.

This follow-up study proposes linking the Clinic's case and comparison data to hospital morbidity and emergency department (ED) records, and death registrations, and to determine whether key outcomes for the Clinic can be measured and monitored using administrative data collections.

Key outcomes include ED presentations, unplanned/planned hospital admissions, length of stay and deaths of enrolled patients. Analyses will provide evidence of the effectiveness of health service delivery in the community. Improvements in clinical outcomes will be assessed by comparing the health status of the study cases before and after enrolment in the Clinic. The study will also compare indicators for the study cases to those of patients who did not enrol in the Clinic (comparison group).

Project Title	Linking data from three national cancer screening programs		
Principal Investigator	Dr Alison Budd		
Institution	Australian Institute of Health and Welfare		
Start Date	13 April 2016	Finish Date	31 December 2021

Australia has three national cancer screening programs—the National Bowel Cancer Screening Program (NBCSP), BreastScreen Australia and the National Cervical Screening Program (NCSP). Data from the three programs have never been linked together to look at participation across the three programs; nor have national breast cancer screening or cervical screening data been linked to the Australia Cancer Database (ACD) or the National Death Index (NDI) to ascertain cancer incidence and mortality outcomes of screened individuals. Therefore, due to the anticipated benefits from linking data from the screening programs together, it has been proposed that the AIHW conduct a research project that links NBCSP, BreastScreen Australia and NCSP data together to form a national screening dataset, and then link this to the ACD, the NDI and the National HPV (Human papillomavirus) Vaccination Program Register (NHVPR).

Project Title	Heatwave related health service demands in WA - Identify vulnerable populations [Short title: Identify vulnerable populations]		
Principal Investigator	Dr Alex Xiao		
Institution	Department of Health		
Start Date	15 June 2016	Finish Date	31 December 2017

Heatwaves have caused more deaths in Australia in the last 200 years than any other natural hazard and is predicted to increase the frequency, duration and intensity thus will lead to increasing heatwave-related deaths in coming years. Currently, there is no standardised definition for heatwave internationally, or even between the different jurisdictions in Australia to link the relationship between heatwave and health service demands. In a recent study we identified that excess heat factor (EHF), which considered a period of acclimatisation as well as the maximum and minimum temperatures, best predicted periods of greatest health service demand along the three indicators examined. One of the limitations of this initial project (phase one) is that the outcomes were based on the whole population in the Perth Metropolitan area. In order to improve current emergency heat management plans in WA, there is a need to recognise vulnerable populations through identifying populations with a high risk of heat exposure. This second phase project aims to characterise the relationships between EHF and health service demand of different population groups. Once the vulnerable populations are identified, pre-warning system then can be targeted to these populations.

Project Title	Improving primary care for Aboriginal mothers and babies in the Kimberley region of Western Australia: a population and region based cluster randomised trial driven by local health service providers [Short title: Nini Helthiwan]		
Principal Investigator	Prof Karen Edmond		
Institution	University of Western Australia		
Start Date	11 May 2016	Finish Date	1 January 2020

There is increasing concern that over 50% of mothers and 60% of breastfed young infants in disadvantaged areas globally have micronutrient malnutrition and iron deficiency anaemia (IDA), with similar rates found in Aboriginal and Torres Strait Islander communities. Despite a decade of substantial investments in Continuous Quality Improvement (CQI) programs, many barriers still remain to the provision of antenatal and postnatal care in remote areas. There have been no studies of the

effectiveness of peer led clinical governance to improve antenatal and postnatal care in remote and disadvantaged communities who are likely to benefit most.

The project has been funded by the National Health and Medical Research Council (NHMRC) to undertake a study of a new locally driven enhanced support model (clinical governance and peer led targeted support) to reduce anaemia rates and improve the quality of maternal and infant primary care. The study will be based in the Kimberley region of Western Australia. The intervention is clinical governance and peer led targeted support for maternal and early infant care delivered by dedicated local midwife coordinators.

This study will evaluate this model of enhanced support using rigorous step wedge approaches and structured questionnaires to assess acceptability, feasibility and sustainability. Our primary outcome measure is improved iron deficiency anaemia in infants aged six months. Secondary outcome measures are improved iron deficiency anaemia in mothers and infants at six months postpartum; improved Bayley neurodevelopmental scores in infants aged six months; improved satisfaction of mothers about maternal health care. The study will also assess the cost effectiveness of the model of enhanced support.

This study will be conducted over a five year period in partnership with service providers in the Kimberley. This is the first population and region based study of clinical governance and targeted peer led support in a remote region. The results of our study will be used to develop improved primary care models and to improve health outcomes for all Aboriginal and/or Torres Strait Islander mothers and infants. These are vital steps towards more equitable health service delivery for Aboriginal and Torres Strait Islander peoples in Australia.

Project Title	Quantifying the Burden of Systemic Sclerosis in Australia: From Data Linkages to Patient- Reported Outcomes		
Principal Investigator	Dr Mandana Nikpour		
Institution	St. Vincent's Hospital Melbourne		
Start Date	26 April 2016	Finish Date	31 December 2018

The true 'burden' of Systemic Sclerosis in Australia remains unquantified, including hospital use, impact on physical function, employment, and quality of life (QoL). This project aims to to quantify the healthcare burden by means of a nationwide 'data linkage' project. The project aims to combine a clinical database that contains data on systemic sclerosis patients with a number of key institutional databases including inpatient hospital admissions; emergency presentations and the medical benefits scheme to determine healthcare use.

Project Title	The Epidemiology of Maternal Mortality and Morbidity in WA, 2001-2014		
Principal Investigator	Dr Teresa Ballestas Barros		
Institution	Department of Health		
Start Date	13 April 2016	Finish Date	30 June 2017

Examination of records of maternal deaths and hospitalisations has been commonly used to assess the quality of health care during pregnancy and identify opportunities for improvement.

In WA, the Maternal Mortality Committee investigates all deaths associated with pregnancy to determine whether, in the opinion of the Committee, the death could have been prevented.

This research project will review the characteristics of maternal deaths and the causes of pregnancy-related hospitalisations from 2001 to the latest year available, with a summary of the Maternal Committee findings and recommendations for the first time since the Committee was created. Publication of results will contribute to medical practice and government policy in this area.

Project Title	Driving health care efficiencies and patient care outcomes by improving communication across acute and primary transitions of care. Phase 1 - Developing unplanned readmissions risk models for elderly and mental health patients.		
Principal Investigator	Prof Phillip Della		
Institution	Curtin University		
Start Date	11 May 2016	Finish Date	30 October 2017

Communication problems are a major contributor to poor outcomes for patients transferring from acute to primary care. This project aims to identify communication and clinical risk factors for readmission and barriers to successful transitions of care for high-risk patient groups including the elderly and mental health patients. The first components of our study are the determination of readmission rates and development of predictive risk models for our target populations based on hospital morbidity and clinical audit data. The study will apply these findings to provide effective, measurable and cost-efficient protocols to improve discharge transition outcomes for patients, carers and health service providers.

Project Title	Reducing inequality in the developmental vulnerability of Australian children: Role of the neighbourhood environment.		
Principal Investigator	Dr Hayley Christian		
Institution	The University of Western Australia		
Start Date	13 April 2016	Finish Date	31 December 2025

Based on the National Progress Measure for early child development (Australian Early Development

Census-AEDC), one quarter of young Australian children are vulnerable to developmental delay. A significant proportion of the variation in developmental vulnerability remains unexplained. Given that the composition and quality of the neighbourhood environment varies markedly across suburbs, not all childhood opportunities are equal. This study will identify risk and protective characteristics of the neighbourhood environment which provide critical intervention points for local communities to reduce children's developmental vulnerability. The findings will provide the evidence-base required to drive national agendas such as the COAG Early Years Learning Framework.

Project Title	Western Australian component of the South Australia and Northern Territory Stroke Study (initial phase) (SAiNTSS1)		
Principal Investigator	A/Prof Timothy Kleinig		
Institution	The University of Western Australia		
Start Date	25 October 2015	Finish Date	31 January 2020

The South Australia and Northern Territory Stroke Study (initial phase) (SAiNTSS1) aims to understand disparities in stroke risk factors, treatment and care, and outcomes between Aboriginal and Torres Strait Islander people and non-Indigenous Australians across SA, NT and WA. The identification of contributors to excess stroke risk and poor outcomes will assist in the development of a range of culturally appropriate primary prevention, secondary prevention and rehabilitation strategies to lessen the stroke burden for Aboriginal and Torres Strait Islander people.

Project Title	A randomised controlled trial to evaluate the effectiveness of SMS immunisation reminders in general practice [Short title: Evaluation of SMS reminders for immunisation]		
Principal Investigator	Ms Annette Regan		
Institution	Department of Health WA		
Start Date	1 May 2016	Finish Date	1 September 2018

Immunisations are an important public health intervention for reducing the morbidity and mortality caused by vaccine-preventable diseases in the community. Certain individuals are at higher risk of serious complications following influenza infection, and unfortunately, influenza vaccine has the worst uptake of any routine vaccination program in Australia. Despite the potential health benefits, approximately 90% of eligible children, 70% of eligible non-elderly adults, and 40% of adults aged 65 and older do not receive an influenza vaccine each year. Previous research has shown the use of text message reminders (also called short message service [SMS] reminders) can be an effective method of promoting influenza vaccine to priority groups. However, the utility of reminders for promoting influenza vaccine has not been well evaluated and the use of SMS immunisation reminders has not been evaluated in Australia. The Western Australia Department of Health (WA Health) is interested in creating a program for general practitioners to routinely use at the beginning of influenza vaccination season to remind patients they are eligible for free influenza vaccine. To assess whether this activity is an effective and efficient use of resources, WA Health intends to evaluate the impact of a prototypic reminder system in a subset of practices. Results will be used to establish systems in Western Australia (WA) for reminding patients annually about influenza vaccination, with the ultimate goal of

promoting health in at-risk groups.

Project Title	Methicillin-resistant Staphylococcus aureus: Its Clinical Significance and Implication on the Western Australian Health System [Short title: MSRA in Western Australia]		
Principal Investigator	Dr Owen Robinson		
Institution	PathWest		
Start Date	11 October 2016	Finish Date	11 October 2019

Methcillin resistant Staphylococcus aureus (MRSA) is a bacteria which causes numerous types of infections in humans and because of its resistance to methicillin, is more complicated to treat. Since its first description in hospitals in the 1960s, MRSA has not only spread throughout all hospitals in the world, but has emerged in the early 1990s as a community pathogen in patients with no contact with the healthcare system. As a result of this, MRSA has become a notifiable diseases in WA and since 1997, all MRSA grown from clinical specimens have been referred to Royal Perth Hospital (RPH) and characterised, giving us a good epidemiological picture of MRSA and it is now recognised that there are numerous different clones of MRSA in WA. However, little clinical information has been collected with these specimens and thus little is known on the true burden of MRSA to the WA population and healthcare system. The aim of this study is to link the MRSA database with the WA Department of Health Hospital Morbidity Data System (HMDS), Emergency Department Data Collection (EDDC), and Death Registry. This will allow the identification of the risk factors for MRSA infections with a stratification per clone, to analyse the hospitalisation rate, length of stay and outcome for each MRSA clone. These data will allow the validation of the current WA infection control operational directive which applies different infection control measure for different MRSA clones based on clinical experience. The cost of MRSA to WA health system will be analysed.

Project Title	The impact of community palliative care on hospital use and place of death among non-cancer decedents [Short title: Impact of community palliative care on non-cancer decedents]		
Principal Investigator	A/Prof Rachael Moorin		
Institution	Silver Chain		
Start Date	1 July 2016	Finish Date	December 2018

Silver Chain's Hospice Care Service (HCS) is the sole provider of community-based palliative care to all of Perth, except the Peel region. This project aims to determine the impact of the HCS on health service use and place of death among Western Australians who have died of conditions other than cancer. Place of death and hospital / emergency department use at the end of life will be compared between those who did and did not access the HCS, among a range of non-cancer decedents.

Project Title	Living with Acute Coronary Syndrome: what happens to people in the early years after discharge from hospital with a coronary event in Australia.		
Principal Investigator	A/Prof Julie Redfern		
Institution	The George Institute for Global Health		
Start Date	9 June 2016	Finish Date	1 December 2020

In May 2012, a 2 week audit was conducted in which data was collected from people admitted to 478 Australian and New Zealand hospitals with a suspected or confirmed acute coronary (ACS) event. The study, ACS SNAPSHOT, showed that only one-quarter of all patients admitted with ACS received optimal secondary prevention (pharmacotherapy, lifestyle advice, and referral to rehabilitation).

The Australian cohort was followed up 18 months later to determine their health outcomes, medication use, service utilisation and the costs involved with living with Acute Coronary Syndrome. This study represents an ideal opportunity to focus on the follow-up care received by Australians living with heart disease to directly inform future clinical practice and policy. To supplement the information collected during the follow up study, we are applying for linkage of Pharmaceutical Benefits Scheme (PBS) and Medicare Benefits Scheme (MBS) data, Admitted Patient Data Collection, Emergency Department Data Collection, and vital status (National Death Index) for the 3391 Australian patients. Linking PBS and MBS data with our current ACS SNAPSHOT database will allow the proportions of patients who have experienced a serious heart event and have since received ongoing medical care and evidence-based medicines to be accurately determined. This study will also examine the outcomes of receiving this care through linkage with hospital admissions, emergency department visits, and the National Death Index. In addition, this study will identify healthcare costs as well as areas and factors associated with reduced access to evidence-based care. Ultimately results from the study will be used to pursue service redesign and policy development with the aim of improving post-discharge preventive care.

Project Title	Is the incidence of heart attack still decreasing in Australia? Developing more reliable methods for monitoring trends in myocardial infarction and coronary heart disease (AUS-MOCHA) [SHORT TITLE: Developing more reliable methods for monitoring trends in myocardial infarction and coronary heart disease]		
Principal Investigator	Dr Frank Sanfilippo		
Institution	The University of WA		
Start Date	16 May 2016	Finish Date	31 December 2018

Background and Aims: Coronary heart disease (CHD) remains a major public health problem, despite declining CHD mortality in Australia over the past 40 years. CHD is comprised of a number of sub-groups of varying clinical severity (myocardial infarction (MI), unstable angina, other angina and other CHD). Studies have shown that the long-term decline in MI incidence and hospitalisation rates since the late 1990s has plateaued. This is partly associated with the introduction of troponin tests - a highly sensitive method for detecting damage to the heart muscle and thus diagnosing MI. Preliminary data for this study showed a potential decrease in the accuracy of administrative data to monitor MI. There are several reasons for this, including a changing clinical diagnosis of MI (use of troponin tests and the shift towards Electrocardiogram (ECG)-based classification of MI) and increasing hospital

presentations for suspected MI (chest pain), but the effects have not been quantified in Australia. This study therefore aims to develop new methods of monitoring population trends in admissions and outcomes of total acute CHD and its major sub-groups.

Design and Methods: This is a population-based cohort study using linked administrative data from the WA Data Linkage System to identify all acute CHD and chest pain events in WA. The core linked dataset (hospital, emergency department and mortality) will have clinical data from pathology laboratories (public and private), and hospital pharmacy databases linked to it. Data will also be collected from a sample of hospital medical notes. This will be used to delineate the two major MI types based on ECG classification - STEMI and NSTEMI.

The main elements of the study include estimating accuracy of the recording of STEMI and NSTEMI in the HMD; measuring incidence and outcomes of different CHD sub-groups which can be accurately identified from linked data; and translation of methods to national data through collaboration with the Australian Institute of Health and Welfare (AIHW). In particular, algorithms will be developed which will provide accurate measurement of CHD and its subgroups using both linked and unlinked data.

Expected outcomes: This study will provide an accurate method for measuring CHD and its sub-groups in administrative data, both using unlinked data and linked data. This will allow reliable national monitoring through our collaboration with the AIHW, and will be useable by other states with varying degrees of linked data infrastructure.

Justification: It is important to measure rates of STEMI and NSTEMI separately because they have different clinical pathways, resource utilisation and outcomes. There is no data in Australia indicating the accuracy of administrative data for the identification of these groups, and minimal data internationally. There is also limited data on the ability of administrative data to provide accurate and consistent trends across the spectrum of CHD. The move towards linked data nationally and in other states means that algorithms for accurately measuring population level trends are required and these will be able to be tested in our WA linked data, as we have longer hospitalisation history in the WADLS (required for incidence and outcome studies).

Project Title	Rheumatic disease conditions as risk factors for hospitalisation, emergency care use, cancer and mortality in Western Australia from 1980 to 2012.		
Principal Investigator	W/Prof Johannes Nossent		
Institution	The University of WA		
Start Date	1 June 2016	Finish Date	1 June 2021

This research aims to investigate the epidemiological characteristics, i.e. trends in hospital-based disease presentations, emergency care utilisation, and cancer development and mortality, in patients with various rheumatic conditions in Western Australia from 1980-2012. This research will highlight the disease burden pertaining to rheumatic disease conditions in WA, e.g. the subsequent risk of complications including the need for joint operations and premature death. The limited availability of specialist services, prompts investigation of health care resource utilisation in WA.

This research will utilise retrospective linked administrative data from all public and private hospitals in WA extracted from the WA Health Data Linkage Branch collections. The cohort under investigation are defined as any person with a listed rheumatic disease condition of interest, i.e. Chronic idiopathic arthritis, spondyloarthopathies, connective tissue disease, crystal arthropathies, vasculidities, and osteoarthrosis, across the period from January 1980 through to December 2012 and across all age ranges. The condition can appear as either principal and/or additional diagnosis/cause of death and can include persons with a previous history of the condition of interest. A control group, drawn from the Electoral Roll, are persons free of the listed conditions; and, alive at the time of the case's index event,

and matched 1:1 for year of birth and gender to the cases across the time period 1980 to 2012.

The period of interest runs from January 1980 through December 2012. This time span encompasses several periods of distinct changes within the scope of Rheumatology such as the widespread introduction of Methotrexate throughout the1990's followed by the introduction of TNF-blockers in 2002 for the treatment of various forms of chronic arthritis. Similar changes occurred with the accepted use of combined steroid and cytotoxic treatment for connective tissue disease and vasculitis in the late 1980's/early 1990's, again followed by the use of B cell depletion therapy since 2002. Although some WA wide databases have a shorter collection period (e.g. emergency data from 2002 only) they will still be of sufficient length of observation.

This research aims to describe and compare the following outcomes in the West Australian context across rheumatic disease conditions including: hospital admission rate trends per decade for cardiovascular events; oncological events; prosthetic joint operations; infectious complications; age and gender specific standardized all-cause mortality rates; emergency department visitations and frequency; and, fractures (all types).

Project Title	WARDA-CP participation in an international collaborative project: An exploration of cerebral palsy in higher order multiples [SHORT TITLE: WARDA-CP participation in a collaborative study of CP in multiples]		
Principal Investigator	Dr Gareth Baynam		
Institution	King Edward Memorial Hospital		
Start Date	1 May 2016	Finish Date	1 December 2017

Multiple birth has already been established as a risk factor for cerebral palsy (CP). In Australia multiple births account for 3.3% of all births but comprise 11.8% of all children with cerebral palsy (ACPR Report, 2013). The exact relationship between multiple pregnancies and CP is poorly understood but involves many complicating factors including preterm birth, low birth weight, placental issues, zygosity, loss of co-multiples ("vanishing twin"), birth order, subfertility and assisted reproductive technology (eg, IVF).

It has been postulated that the risk of CP increases with the number of fetuses in a pregnancy. Two studies in the United Kingdom (UK) and Western Australia found the risk of CP in triplets to be more than three times that for twins (Pharaoh and Cooke, 1996; Petterson et al, 1993). Given the relative infrequency of higher order multiples, the actual numbers of cases are very small – in both studies only six cases of CP in triplets were found – and much larger populations are required to more accurately establish the prevalence and characteristics of these children.

The Australian Cerebral Palsy Register (ACPR) is a database of de-identified information about children with CP contributed by each state/territory. The Surveillance of Cerebral Palsy Europe (SCPE) is a similar network of CP surveys and registers in Europe, holding data from 21 geographical regions. This collaborative study aims to explore the prevalence of CP in twins and higher order multiples using de-identified data from the ACPR and SCPE, along with denominator data regarding births in the Australian and European jurisdictions.

Non-identifiable line data for cases born 1993-2009 from a twin or higher order multiple birth held on the ACPR (Australian population-level States only: South Australia, Victoria and Western Australia) will be exported from the ACPR and sent by secure file transfer to our SCPE collaborators in France. The State from which data were obtained will not be identified. These data will be pooled with data from participating European registers to calculate the prevalence of CP by plurality and describe the group of triplets and higher order multiples with CP compared with those from twin pregnancies.

As WA has the longest established CP Register in Australia with a high level of case ascertainment,

WARDA-CP data are essential to the collaboration.

Project Title	**The impact of first and second eye cataract surgery on crash risk**		
Principal Investigator	Prof Lynn Meuleners		
Institution	Curtin University		
Start Date	8 June 2016	**Finish Date**	1 June 2017

Cataract is the leading cause of reversible vision impairment in developed countries and by the age of 70 years, almost everyone will have developed some degree of cataract. The study will use linked population health data to examine and provide accurate information on the impact, benefits and cost-benefits of first and second eye cataract surgery on crash risk for an older population. The research will be retrospective (looking backwards) and population based. It will make use of data from the Western Australian Hospital Morbidity Data System (to obtain details of those undergoing cataract surgery from 2004-2014), the Western Australian Mortality Database (to identify those who died during the study period 2004-most recent); as well as Main Roads crash database to identify those who had a crash during the study period - one year before and one year after which will be 2003 to most recent). Data will also be obtained from Licensing at the Department of Transport to determine which participants who had bilateral cataract surgery were licensed to drive a motor vehicle. These databases will then be linked by the Data Linkage Branch at the Department of Health, Western Australia. The study will provide ophthalmologists, road safety experts and road licensing authorities with evidence-based guidelines to improve road safety for the growing older driver population with cataract, reducing the financial burden associated with older driver crashes.

Project Title	**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 [SHORT TITLE: Tailored Patient Education for Preventing Falls after Hospital Discharge]**		
Principal Investigator	Dr Anne-Marie Hill		
Institution	Curtin University		
Start Date	31 July 2015	**Finish Date**	1 December 2018

Older people are at increased risk of falls after hospital discharge causing unplanned hospital readmissions and hip fractures. However they have low levels of knowledge about falls and are reluctant to engage in falls prevention activities. Despite this, there is limited knowledge about the economic costs of falls in this cohort and no clinical trials have investigated whether providing high quality education for older patients prior to discharge can reduce falls in the high risk hospital to home transition period.

The primary aim of this trial is to determine if providing tailored falls prevention education consisting of multimedia materials with individual health professional follow-up in hospital and after discharge (by telephone calls) reduces falls rates in older people after discharge from hospital. The secondary outcomes measured are health-related quality of life and functional activity. An economic evaluation is also conducted to determine if patients who fall after discharge from hospital incur more health care

costs compared to those who don't fall.

Project Title	Baseline for monitoring the burden of rheumatic heart disease in Australian jurisdictions: Western Australian component [SHORT TITLE: Burden of rheumatic heart disease in Western Australia]		
Principal Investigator	A/Prof Judith Katzenellenbogen		
Institution	Telethon Kids Institute		
Start Date	1 July 2016	Finish Date	31 December 2020

Rheumatic heart disease (RHD) is a preventable condition which has its origins in a childhood bacterial infection eliciting an auto-immune response called acute rheumatic fever. This may cause lifelong heart valve problems leading to RHD. RHD rates reported for Australian Aboriginal people are among the highest in the world. Using linked hospital, death, RHD register and infectious diseases notification data, this proposal addresses the need for more comprehensive data for RHD to monitor changes in RHD in different Australian jurisdictions. Results will include the incidence of acute rheumatic fever, progression to RHD, prevalence of RHD and factors determining complications such as stroke, atrial fibrillation and premature death. Similar data will be obtained from other jurisdictions which have RHD registers; Northern Territory, Queensland, New South Wales and South Australia.

Project Title	Describing microcephaly in Western Australia: baseline data in response to Zika Virus concerns. [Short title: Epidemiology of microcephaly in WA]		
Principal Investigator	Dr Michele Hansen		
Institution	Telethon Kids Institute		
Start Date	18 May 2016	Finish Date	18 May 2017

Zika virus has come to world attention since reports emerged from Brazil in 2015 of its association with a large increase in cases of microcephaly in newborn babies. Microcephaly is a condition where a baby's head is much smaller than expected for its age, sex and race. Affected children may suffer from a range of problems depending on the severity of the microcephaly including epilepsy, developmental delay, intellectual disability, vision and hearing problems.

Zika virus is generally transmitted to humans by the bite of infected mosquitos. There is no available vaccine for Zika virus, no specific treatment and no rapid diagnostic test. The World Health Organization recently declared the cluster of microcephaly cases and other neurological disorders reported in Brazil a 'Global Emergency' amidst concern over possible links between Zika infection during pregnancy and birth defects as well as the rapid spread of the Zika virus to other countries in the Americas, and the broad geographical spread of mosquito species that are capable of transmitting the virus.

We propose a population-based study of all infants born in Western Australia (WA) between 1980 and 2015 diagnosed with microcephaly and notified to the WA Register of Developmental Anomalies. The aim is to describe the prevalence of this birth defect over time in Western Australia, sources of notification, birth characteristics, causes (where known), and any associated birth defects found in these children. The WARDA is an internationally respected statutory data collection of information

about birth defects and cerebral palsy diagnosed in Western Australia. The recent outbreak of the Zika virus in Brazil and reported association with increased prevalence of microcephaly has highlighted the need for adequate baseline epidemiological data about this birth defect in preparation for enhanced surveillance of microcephaly internationally.