



Government of Western Australia  
Department of Health

# Human Research Ethics Committee

Project Summaries for Approved  
Proposals

April to June 2015 Quarter

**Project summaries for proposals approved by the Department of Health Human Research Ethics Committee – April to June 2015 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 summaries available for the April to June 2015 quarter.

<b>Project Title</b>	<b>Heritable and environmental determinants of hospitalisation for common childhood illnesses - Study 1: association between non-twin siblings in hospital admissions.</b>		
<b>Principal Investigator</b>	Professor Nick De Klerk		
<b>Institution</b>	Telethon Kids Institute		
<b>Start Date</b>	19 May 2015	<b>Finish Date</b>	31 December 2017
<p>Infectious diseases are the leading cause of childhood death and health service use worldwide. Why some children develop more severe infection is largely unknown. The relative contribution of genetic and environmental factors to common childhood infections severe enough to require hospitalisation is largely unexplored. This is the overall aim of this project. In this first study of the broader project, these questions will be examined using WA population-level hospital admission data for brothers and sisters, but will exclude twins and multiples. In the second distinct and separate part of the study, these questions in twin families will be examined.</p>			

<b>Project Title</b>	<b>Modelling predictors of hospital demand to improve clinical service planning, intervention evaluation and performance management</b>		
<b>Principal Investigator</b>	Associate Professor David Whyatt		
<b>Institution</b>	University of Western Australia		
<b>Start Date</b>	1 July 2015	<b>Finish Date</b>	30 June 2018
<p>A major challenge in delivering health care services is determining the predictors of health outcomes, including hospital admissions, emergency department presentations and mortality. Determining such predictors is important for answering questions in healthcare delivery, including clinical service planning ('where should services be placed?'), intervention evaluation ('what services are effective?') and performance management ('how do we measure effective service delivery?'). This project applies advanced statistical and mathematical techniques to health utilisation, geographical and demographic data, to answer these questions.</p>			

<b>Project Title</b>	<b>A comparison of the physical activity and sedentary time levels and patterns of cancer survivors and the general population</b>		
<b>Principal Investigator</b>	Dr Terry Boyle		
<b>Institution</b>	University of Western Australia		
<b>Start Date</b>	1 March 2015	<b>Finish Date</b>	30 June 2016
<p>The aim of this study is to investigate if the physical activity and sedentary time levels and patterns of cancer survivors differ to those of the general population. The evidence from previous research that has investigated this issue is mixed and has generally been based on self-reported estimates of physical activity, which are inaccurate and prone to overestimation.</p> <p>The physical activity and sedentary time data that will be used in this study has been collected using accelerometers, which are devices that provide valid and reliable information about physical activity and sedentary time levels and patterns. This study only involves analysis of existing collections of data. The data for the cancer survivor groups comes from previous studies of colon cancer survivors, non-Hodgkin lymphoma survivors and breast cancer survivors that were conducted in Western Australia and Alberta, Canada. The data from the general population comes from the Australian Diabetes, Obesity and Lifestyle (AusDiab) Study, a cohort study that is coordinated by the Baker IDI Heart and Diabetes Institute in Melbourne, Victoria.</p>			

<b>Project Title</b>	<b>A multinational comparison of hospitals, ICU admissions and mortality rates amongst the very elderly</b>		
<b>Principal Investigator</b>	Dr Matthew Anstey		
<b>Institution</b>	Sir Charles Gairdner Hospital		
<b>Start Date</b>	1 February 2015	<b>Finish Date</b>	1 February 2017
<p>In many countries the availability of intensive care resources is both limited and expensive. Intensive care unit (ICU) clinicians may be forced to choose the patients that would gain the most from ICU admission. The elderly represent an increasing sub-group of patients admitted to ICUs who may be at increased risk of worse outcomes, due to their age. However other factors such as the presence of co-morbidities, functional impairment and whether the admission is elective or an emergency seem to have greater influence on the outcome. The availability of ICU beds varies across regions and countries, as do the number of admissions.</p> <p>This study aims to look at the characteristics of patients older than 80 years of age who are admitted to hospital or the ICU in three different regions. This is in order to see whether there is a difference in their mortality at one and two years after admission and if a more liberal ICU admissions policy is associated with a higher survival rate.</p>			

<b>Project Title</b>	<b>Juvenile melanomas: Western Australia melanoma advisory service experience</b>		
<b>Principal Investigator</b>	Dr Jie Xin Xu		
<b>Institution</b>	Western Australian Melanoma Advisory Service (WAMAS)		
<b>Start Date</b>	31 January 2015	<b>Finish Date</b>	31 December 2015
<p>This study aims to establish any clinical patterns in demographics, pathology and prognosis which may aid diagnosis or prediction of paediatric melanoma development. Though the incidence of childhood melanoma is very low, it is a life threatening disease and despite the increasing incidence of melanoma in children and adolescents, there remains a paucity of research. More importantly, there are a lack of studies in the Australian paediatric population, which is home to one of the highest incidences of melanoma worldwide. Currently, there is less well established practice guidelines for paediatric and adolescent melanoma compared to adult populations and much more research is needed to help resolve diagnostic ambiguity, which may lead to targeted melanoma treatment for children and adolescents.</p> <p>The study design of this project is a retrospective cohort study. This involves the retrospective analysis of medical and pathology reports that were prospectively collected from a cohort of patients in the Western Australian paediatric population that had developed melanoma. Using this information, the clinical features of childhood melanoma will be characterised. In particular, the trends in age, gender, melanoma subtype, ethnicity, body site, lymph node involvement, and metastasis will be analysed. From this analysis the aim is to establish if any certain feature(s) are more prone to delay in presentation, recurrence and poor prognosis.</p>			

<b>Project Title</b>	<b>Statewide implementation of cervical length screening for the prevention of preterm birth</b>		
<b>Principal Investigator</b>	Professor Jan Dickinson		
<b>Institution</b>	University of Western Australia		
<b>Start Date</b>	1 March 2015	<b>Finish Date</b>	30 June 2017
<p>Preterm birth (delivery less than 37 weeks' gestation) affects 8 - 9 % of all births in Western Australia. It is the leading cause of perinatal morbidity and mortality and has significant long-term adverse outcomes in children. Until recently, there was no proven intervention to prevent preterm birth. It is recognised that a short cervix is the best predictor for an increased risk of preterm birth. Recent randomised controlled trials have demonstrated that the administration of progesterone to women with a short cervix can reduce preterm delivery by up to 50%. Cervical length screening with ultrasound is now recommended to identify women at risk of preterm delivery, particularly those with additional risk factors (eg. prior preterm birth, previous cervical surgery).</p> <p>Specifically, this research project will aim to assess the acceptance and understanding of cervical length screening in pregnant women and the current opinions, knowledge and understanding of the role of cervical length screening in preterm birth prevention by obstetric care providers. The measurement reproducibility of the ultrasound technique for cervical length assessment will be assessed by providing radiologists and sonographers with a series of ultrasound images for their interpretation.</p>			

<b>Project Title</b>	<b>Mammographic density in families with high-risk of breast cancer</b>		
<b>Principal Investigator</b>	Associate Professor Jennifer Stone		
<b>Institution</b>	University of Western Australia		
<b>Start Date</b>	1 May 2015	<b>Finish Date</b>	1 December 2018
<p>Breast cancer is the most common cancer in Australian women and is heritable. Mammographic density is one of the strongest risk factors for breast cancer risk and is also heritable. As mammographic density can be measured in anyone willing to undergo mammography, it has enormous potential as an intermediate phenotype in which to identify novel genetic variants associated with breast cancer risk, particularly in pedigree-based studies.</p> <p>The Kathleen Cuninghame Foundation Consortium for Research into Familial Breast Cancer (kConFab Consortium) has been collecting genetic and epidemiological data from Australian families with a strong history of breast cancer since 1997 and has accumulated data on more than 1400 multigenerational, multi-case kindreds. This study will measure mammographic images from almost 1300 women from high-risk families participating in the kConFab Consortium. Our goal is to identify informative families for further genetic research to identify novel genetic variants associated with mammographic density and/or breast cancer risk.</p>			

<b>Project Title</b>	<b>Rheumatic diseases as a risk factor for hospitalisation, emergency care use, cancer and mortality in Western Australia [Short title: Epidemiology of rheumatic disease conditions in WA]</b>		
<b>Principal Investigator</b>	Winthrop Professor Johannes Nossent		
<b>Institution</b>	University of Western Australia		
<b>Start Date</b>	18 February 2015	<b>Finish Date</b>	18 February 2025
<p>This project aims to describe trends in hospital-based disease presentations, the need for emergency care, and cancer development and mortality in patients with various rheumatic conditions in Western Australia over the period 1980 - 2012. The projects aims to measure the rheumatic disease burden and subsequent risk of chronic diseases, the need for joint operations and early death in Western Australia (WA). Given the limited availability of specialist services, the aim is to also determine the impact on the use of health care resources in WA. The study is designed as a retrospective whole population cohort study using linked administrative data from all public and private hospitals in WA.</p> <p>The aims are to describe and compare the following outcomes in the WA context across rheumatic disease conditions: hospital admission rate trends per decade for cardiovascular events; oncological events; prosthetic joint operations; infectious complications; age and gender specific standardised all-cause mortality rates; emergency department visitations and frequency; and fractures (all types).</p>			

<b>Project Title</b>	<b>Evaluation of Moorditj Djena program</b>		
<b>Principal Investigator</b>	Dr Anna Beswick		
<b>Institution</b>	Department of Health		
<b>Start Date</b>	1 May 2015	<b>Finish Date</b>	29 February 2016
<p>The Aboriginal Podiatry and Nutrition Outreach Program (Moorditj Djena) is run through the South Metropolitan Health Service in Perth. The aim of this program is to provide a culturally secure, 'high-risk foot' and diabetes education outreach service for Aboriginal people that identifies, manages and prevents foot complication associated with chronic disease and imparts, when indicated, the principles of diabetes self management.</p> <p>The program has been running since January 2011 and has assisted with the care of over 900 people. The project will evaluate this service by comparing hospitalisations of those at high risk of foot complications, both before and after enrolment with the program. The aim is to see if patients enrolled in the program attend hospital less or have shorter length of stays whilst in hospital for diabetes related conditions (excluding renal dialysis). This will be used to estimate the economic impact of the program.</p>			

<b>Project Title</b>	<b>Linked perinatal, birth, death data set project</b>		
<b>Principal Investigator</b>	Dr Fadwa Al-Yaman		
<b>Institution</b>	Australian Institute of Health and Welfare		
<b>Start Date</b>	1 August 2015	<b>Finish Date</b>	Ongoing
<p>The main aim of the project is to create a national, linked perinatal, registered births and registered deaths dataset containing information. This will enable Australian Institute of Health and Welfare researchers to answer key questions pertaining to differentials in birth and health outcomes up to five years after birth, particularly infant and child mortality, between Indigenous and non-Indigenous status.</p>			

<b>Project Title</b>	<b>Maternal satisfaction with maternity services (MSMS) phase 2 (for public purposes 'women's maternity care experiences')</b>		
<b>Principal Investigator</b>	Dr Tracy Reibel		
<b>Institution</b>	Telethon Kids Institute		
<b>Start Date</b>	1 May 2015	<b>Finish Date</b>	Ongoing
<p>The broader goal this project seeks to achieve is to provide a means of validly and reliably measuring women's maternity care experiences in Western Australia, establishing a sound basis for community and hospital quality improvement processes and giving the Department of Health Statewide Obstetric Services Unit a tool for planning and monitoring outcomes in a core area of maternity care policy (i.e. women's views of quality).</p> <p>The project is being done in phases; 1) the development and testing of a survey tool; 2) research to determine the processes required to use the survey at an individual service level; and, 3) research to establish the requirements of specific sub-groups of women to ensure their equitable inclusion in future survey dissemination.</p> <p>Work to date has addressed an evidence gap in the measurement of women's satisfaction with maternity care and providing a theoretically based instrument. The current phase of the project (phase 2) is focussed on developing a detailed user guide to assist health services to use the survey tool developed in the first phase of the project.</p>			

<b>Project Title</b>	<b>The Western Australian Ophthalmic Tumour Registry and Biobank: Retrospective collection of demographic, clinical and pathological information as well as genetic material from patients with tumours of the eye, orbit and ocular adnexae</b>		
<b>Principal Investigator</b>	Associate Professor Adam Gajdatsy		
<b>Institution</b>	Lions Eye Institute		
<b>Start Date</b>	1 May 2015	<b>Finish Date</b>	Ongoing
<p>Uveal melanoma is the most common malignant tumour arising within the eye. Up to half of affected patients die as a result of tumour spread to other organs, particularly the liver. At present, there is no comprehensive registry of the demographic, clinical and pathological features of uveal melanoma diagnosed in Western Australia. This project will aim to:</p> <ol style="list-style-type: none"> <li>1. Establish a registry resource for research into uveal melanoma;</li> <li>2. Facilitate a series of research projects into the aetiology, detection, development of new therapies, genetic risk and risk of metastasis; and</li> <li>3. Provide a resource for researchers internationally.</li> </ol>			

<b>Project Title</b>	<b>Neurodevelopmental and other outcomes in children with congenital heart defects in Western Australia</b>		
<b>Principal Investigator</b>	Dr Caroline Bower		
<b>Institution</b>	Telethon Kids Institute		
<b>Start Date</b>	6 May 2015	<b>Finish Date</b>	Ongoing
<p>About 1.4 million infants are born every year around the world with congenital heart defects (CHD), which is the most common birth defect. Although improvements in survival and health outcomes for CHD infants have been made, children with these defects still have serious long-term health issues that require multiple surgeries, hospitalisations and doctor visits. Children with CHDs are at risk of significant neurodevelopmental and cognitive problems during infancy and childhood and many problems remain during adolescence and in adulthood. Thus, CHDs pose a significant emotional, psychological, social and financial burden on families and society.</p> <p>Recently, mandatory newborn screening of all infants with pulse oximetry prior to hospital discharge has been recommended in the United States and countries in the United Kingdom, Europe and Asia are also considering adopting similar screening guidelines. Pulse oximetry is a low-cost and non-invasive recommended screening method to detect critical congenital heart defects (CCHDS) in newborns since infants with a CCHD have significant increased risk for mortality and disability if the defect is not diagnosed and treated soon after birth. This retrospective cohort study will link 1980 - 2013 data on approximately 9,500 children with CHDs from the Western Australian Register for Developmental Anomalies to education and health databases in Australia to address the following specific aims:</p> <ol style="list-style-type: none"> <li>1. Determine the neurodevelopmental and academic outcomes among children with CHDs in comparison to unaffected children;</li> <li>2. Assess whether specific clinical characteristics are associated with neurodevelopmental and academic outcomes in children with CHDS; and</li> <li>3. Estimate the effect of pulse oximetry screening for CCHD on mortality, morbidity, and neurodevelopmental and academic outcomes among children in Western Australia.</li> </ol>			

<b>Project Title</b>	<b>In situ HER2 gene transcript detection in breast cancer tissue specimens</b>		
<b>Principal Investigator</b>	Assistant Professor Katie Meehan		
<b>Institution</b>	University of Western Australia		
<b>Start Date</b>	30 April 2015	<b>Finish Date</b>	30 April 2016
<p>Hormone receptors and human epidermal growth factor receptor 2 (HER2) are the most commonly used prognostic biomarkers in the routine pathological assessment for breast cancer. Whilst testing of hormone receptors is straight forward, HER2 status requires more complex testing and current methodologies are controversial. Accurate HER2 testing is critical because it guides treatment. The use of a novel test to accurately establish HER2 status has been explored. The aim of this study is to perform a retrospective cohort study for in situ transcript detection on routine formalin-fixed paraffin-embedded breast cancer specimens.</p>			

<b>Project Title</b>	<b>A study of prolific offenders in Western Australia</b>		
<b>Principal Investigator</b>	Associate Professor Anna Ferrante		
<b>Institution</b>	Curtin University		
<b>Start Date</b>	1 July 2015	<b>Finish Date</b>	1 July 2016
<p>This study proposes an investigation of the risk factors associated with high-rate or 'prolific' offending in Western Australia. Making use of linked data from health, child-protection, education and the justice sector, the study seeks to:</p> <ol style="list-style-type: none"> <li>1. Identify and describe the population of prolific offenders in Western Australia (those born between 1980 and 1995, and followed to 2005);</li> <li>2. Identify the factors that distinguish prolific offenders from other offenders in Western Australian population; and</li> <li>3. Examine whether these correlate or predictors of prolific offending are similar for male and female offenders, and for other sub-categories of offenders (e.g. violent/non-violent).</li> </ol>			

<b>Project Title</b>	<b>Pregnancy-related medical services utilisation and perinatal outcomes in Western Australia (WA) with a focus on recent migrants [Short title: Pregnancy-related health services and outcomes in relation to maternal country of birth]</b>		
<b>Principal Investigator</b>	Professor David Preen		
<b>Institution</b>	University of Western Australia		
<b>Start Date</b>	1 July 2015	<b>Finish Date</b>	31 December 2019
<p>Immigration is the principal component of population growth in Australia. However, ethnicity as a predictor of pregnancy outcomes has received limited research attention and the status of reproductive health migrants in Australia has not thoroughly been explored. Using linked health data, this study aims to explore pregnancy-related health services utilisation and outcomes among the Western Australia population with a special focus on recent migrants and also to further investigate perinatal outcomes such as preterm birth, birthweight and perinatal death.</p>			

<b>Project Title</b>	<b>Western Australian health and pregnancy survey [Short title: Health and pregnancy survey]</b>		
<b>Principal Investigator</b>	Dr Paula Wyndow		
<b>Institution</b>	Telethon Kids Institute		
<b>Start Date</b>	1 May 2015	<b>Finish Date</b>	1 May 2016
<p>Efforts to tackle lifestyle risk factors are beneficial at any life stage, but even more so during the perinatal period where the interplay between environment, social and physical factors can impact on maternal health and birth outcomes and the health and wellbeing of both mother and child. Pregnancy complications and birth defects have been linked to a range of risk factors such as smoking, alcohol, obesity, poor or inadequate nutrition, drugs, violence, chronic disease and fertility treatment.</p> <p>The overall aim of this project is to provide invaluable data of the prevalence of pregnancy health behaviours and risk factors for a range of birth defects and other adverse maternal and infant outcomes within Western Australia (WA). To do this a sample of women throughout WA who have recently given birth will be surveyed where they will be asked what they know about having a healthy pregnancy and about their health and lifestyle behaviours prior to and during pregnancy. This study will provide an ongoing vehicle for identifying health needs and evaluating the behavioural impact of state-wide and targeted health promotion, and other interventions for pregnant women. It will inform policy and practice and allow for more targeted approaches to high risk populations.</p>			

<b>Project Title</b>	<b>BCEES Collaborations</b>		
<b>Principal Investigator</b>	Associate Professor Jennifer Stone		
<b>Institution</b>	University of Western Australia		
<b>Start Date</b>	1 January 2015	<b>Finish Date</b>	31 December 2017
<p>This project will contribute Cancer Registry data obtained as part of the Breast Cancer Environment and Employment Study (BCEES) to international collaborative research projects. BCEES was a population-based case-control study in Western Australia from 2009 - 2011 with 1205 incident breast cancer cases and 1789 frequency age-matched controls. The BCEES study consists of questionnaire data, Cancer Registry data, saliva samples, DNA, genotyping data, mammographic images, and mammographic density data. In order to maximise the value of the BCEES data, we are now participating in several international collaborations designed to identify predictors of breast cancer risk.</p>			

<b>Project Title</b>	<b>Hysterectomy, oophorectomy and chronic disease outcomes</b>		
<b>Principal Investigator</b>	Dr Susan Jordan		
<b>Institution</b>	QIMR (Queensland Institute of Medical Research) Berghofer Medical Research Institute, Royal Brisbane Hospital		
<b>Start Date</b>	1 August 2015	<b>Finish Date</b>	1 August 2018
<p>Up to 35% of Australian women have a hysterectomy, often with the removal of one or both ovaries, so it is important we understand the long term consequences of these procedures including effects on future cancer incidence and other chronic disease. This study will use information collected over a 40-year period to assess the effect of this type of surgery on the risk of specific types of cancer (ovary, breast and colorectal) and other important health outcomes (hip fracture and mortality) taking into consideration women's ages at surgery and the reasons for their surgery.</p>			



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