



Government of Western Australia  
Department of Health

# Human Research Ethics Committee

## Project Summaries for Approved Proposals

January to March 2014 Quarter

**Project summaries for proposals approved by the Department of Health Human Research Ethics Committee – January to March 2014 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 January to March 2014 quarter.

<b>Project Title</b>	<b>Pneumococcal meningitis in Western Australian children 1990-2013: clinical course, resource use, outcome, epidemiology, microbiology and the effect of widespread vaccination.</b>		
<b>Principal Investigator</b>	Dr Elysia Manley		
<b>Institution</b>	Princess Margaret Hospital		
<b>Start Date</b>	30 June 2013	<b>Finish Date</b>	31 December 2014
<p>Bacterial meningitis is one of the most serious infections in children. This project will involve undertaking a retrospective study of children aged 16 years and younger who were diagnosed with pneumococcal meningitis in Western Australia between 1990 and 2013. Patient demographics, risk factors, clinical course, microbiological data, treatment and outcome will be collected and analysed to identify changes that have occurred since the introduction of widespread vaccination. The vaccination became available for Indigenous children in 2001 and for non-Indigenous children in 2005.</p>			

<b>Project Title</b>	<b>Childhood developmental pathways to educational achievement in Western Australia: a multilevel data linkage study</b>		
<b>Principal Investigator</b>	Dr Rebecca Glauert		
<b>Institution</b>	Telethon Kids Institute		
<b>Start Date</b>	30 September 2013	<b>Finish Date</b>	1 July 2018
<p>This project aims to examine the developmental pathways related to educational achievement for Western Australian children. Using linked data analysis, the project will combine data on neighbourhood, parent, and individual characteristics to investigate the risk and protective factors associated with performance on the Australian Early Development Index (AEDI) at age 5 and the National Assessment Program - Literacy and Numeracy (NAPLAN) at age 8. The study will also examine the utility of using AEDI scores to predict later performance on NAPLAN.</p>			

<b>Project Title</b>	<b>A randomised controlled trial testing the efficacy and cost benefit of cognitive behavioural therapy on the health outcomes of chronic obstructive pulmonary disease patterns</b>		
<b>Principal Investigator</b>	Dr Natalie Strobel		
<b>Institution</b>	Edith Cowan University		
<b>Start Date</b>	1 November 2012	<b>Finish Date</b>	30 April 2015
<p>Chronic obstructive pulmonary disease (COPD) is an irreversible lung disease characterised by airflow obstruction. Symptoms of COPD include breathlessness, a chronic cough and sputum production. COPD is complicated by a number of other diseases experienced by patients, particularly anxiety disorders and depression. Psychological distress is experienced by a large number of people with COPD, with international evidence estimating 37% of COPD patients suffer from anxiety and 40% from depression. Furthermore, COPD patients with anxiety disorders have a poorer quality of life, higher death rates, more hospitalisations and emergency visits, and are a greater economic burden.</p> <p>The aims of this project are:</p> <ol style="list-style-type: none"> <li>1. to determine the impact of healthcare utilisation in COPD patients with and without anxiety disorders and depression two years prior to entering the study.</li> <li>2. to demonstrate the provision of cognitive behavioural therapy (CBT) of simulation-based learning resources (e.g. DVDs) improves health outcomes among COPD patients.</li> <li>3. to determine the impact on healthcare utilisation (cost) of treating anxiety disorders and depression in COPD patients.</li> </ol> <p>It is expected that simulation-based learning resources will reduce anxiety disorders and depression among COPD patients compared to CBT and usual care and that this will reduce healthcare utilisation.</p>			

<b>Project Title</b>	<b>Identifying genetic risk factors for mammographic density in extended pedigrees in the Busselton Health Study</b>		
<b>Principal Investigator</b>	Associate Professor Jennifer Stone		
<b>Institution</b>	The University of Western Australia		
<b>Start Date</b>	1 January 2014	<b>Finish Date</b>	31 December 2017
<p>The aim of this project is to identify genes that are associated with mammographic density, one of the strongest predictors of breast cancer risk, using data from the Busselton Health Study. This project will exploit the large pedigrees in the Busselton Health Study and utilise data collected as part of the Busselton Health Study (genetic data and questionnaire data), BreastScreen WA (mammograms and breast cancer risk factor data), the WA Cancer Registry (breast cancer incidence and pathology variables) and the Death Registry (date and cause of death) linked via the Western Australia Data Linkage System.</p>			

<b>Project Title</b>	<b>Acute rheumatic fever increase in Western Australia</b>		
<b>Principal Investigator</b>	Ms Janice Forrester		
<b>Institution</b>	Kimberley Population Health Unit		
<b>Start Date</b>	28 February 2014	<b>Finish Date</b>	28 February 2015
<p>Acute Rheumatic Fever (ARF) may follow infection with a bacteria named group A Streptococcus. ARF affects many organs, but most importantly can affect the heart valves, resulting in Rheumatic Heart Disease. ARF is a condition that can be prevented through medications and improved living conditions. Doctors need to complete a notification when they think a person is affected by ARF. Over the past 12 months, doctors have reported many more cases of ARF across WA, but mostly in Perth, Broome and Fitzroy Crossing.</p> <p>This increase in numbers of ARF may be because there is more education of doctors and they are better at recognising and reporting ARF. However, Princess Margaret Hospital is also reporting that they are seeing more severe cases of ARF, and children are requiring heart surgery sooner. This supports the idea that there is a changing pattern of ARF in Western Australia.</p> <p>This project will investigate whether there really are more cases of ARF occurring in WA. This will be done by looking at ARF notification data and data from ARF related hospitalisations to establish the baseline rate of ARF in WA since 2001. Current numbers of ARF cases will be compared with numbers of cases from previous years to establish whether a true increase has occurred (a disease outbreak).</p>			

<b>Project Title</b>	<b>The Australian rare diseases survey</b>		
<b>Principal Investigator</b>	Ms Caron Molster		
<b>Institution</b>	Department of Health		
<b>Start Date</b>	4 March 2014	<b>Finish Date</b>	4 June 2014
<p>A rare disease is a life-threatening or chronically debilitating disease that occurs infrequently in the population and requires special combined efforts to be managed effectively. While each disease affects relatively few people, collectively, they affect 6-8% of the population.</p> <p>International studies and anecdotal evidence in Australia suggests that those living with a rare disease face many problems navigating the health system including lack of access to the correct diagnosis, lack of information and scientific knowledge, lack of appropriate, quality health care, inequitable access to drugs and treatments and social consequences such as isolation and exclusion from the community.</p> <p>The purpose of this study is to explore the healthcare experiences of people living with a rare disease and their families and carers within Australia. The survey will focus on identifying and understanding the perspectives of those living with a rare disease and will examine areas of healthcare provision including research, diagnosis and use of healthcare services, information, support and treatment.</p>			

<b>Project Title</b>	<b>Compliance of post radiation therapy head and neck cancer patients with caries preventative protocols</b>		
<b>Principal Investigator</b>	Associate Professor Agnieszka Frydrych		
<b>Institution</b>	The University of Western Australia		
<b>Start Date</b>	1 April 2014	<b>Finish Date</b>	1 April 2015
<p>This project will study records of patients referred to a public oral medicine clinic at the Oral Health Centre of WA (School of Dentistry, UWA) from a head and neck oncology unit of a major Western Australian teaching hospital. The patients were referred between January 2005 and December 2011. This project will include the examination of about 300 records of adult patients, who are predominantly male. Data extracted will include descriptive and treatment variables as well as outcome variables. The main outcome variables will include use of fluoride, regular dental care, oral hygiene and dietary advice.</p>			

<b>Project Title</b>	<b>An exploratory study of participants' experiences and views of altruistic surrogacy</b>		
<b>Principal Investigator</b>	Dr Maureen Harris		
<b>Institution</b>	Department of Health		
<b>Start Date</b>	12 March 2014	<b>Finish Date</b>	12 March 2015
<p>Surrogacy is an arrangement where a woman agrees to carry, give birth, and then relinquish the child to the arranged parent/s. Altruistic surrogacy has been legal in Western Australia since 2009, but little is known about the context and process of securing a surrogacy arrangement. This exploratory study seeks to shed light on the experiences and views of people who have been or are currently involved in altruistic surrogacy arrangements in Western Australia. Data will be collected by interview to provide narrative accounts, which will be transcribed. The text will be reviewed and coded using a qualitative software program to identify recurrent themes and issues. This study will help to shed light on a complex life event, and this knowledge will be of immense value to future surrogacy applicants, health professionals and policy makers. It will help increase public understanding of altruistic surrogacy.</p>			

<b>Project Title</b>	<b>The impact of using sampling methods to minimise disclosure risk in studies using linked administrative data</b>		
<b>Principal Investigator</b>	Prof David Lawrence		
<b>Institution</b>	Telethon Kids Institute		
<b>Start Date</b>	30 November 2013	<b>Finish Date</b>	30 November 2014
<p>This project aims to determine whether samples of the full population data can be used to calculate accurate and reliable estimates of population parameters in analyses using data from the Western Australian Linked Data System. Previous work has established that sampling methods can be used to estimate population rates with acceptable accuracy in some situations. The current project aims to extend this work by testing this methodology using multiple datasets, and more complex analytic techniques and case definitions.</p>			

<b>Project Title</b>	<b>Validation and impact of the four hour rule in the emergency department: a large data linkage study</b>		
<b>Principal Investigator</b>	Dr Roberto Ferero		
<b>Institution</b>	University of New South Wales		
<b>Start Date</b>	1 March 2014	<b>Finish Date</b>	31 December 2016
<p>The purpose of the project is to assess the effectiveness of the Western Australian Four Hour Rule Program in reducing access block and overcrowding in emergency departments. Additionally, this project will evaluate the impact of the intervention on patient outcomes. The four hour rule was implemented in Western Australian hospitals before other states and the project will examine the characteristics and outcomes of patients before, during and after implementation of the policy in Western Australia. The aim of the Western Australian Four Hour Rule Program was to achieve 90% compliance by 2011. The policy intent of the Four Hour National Emergency Access Target program is that by 2015, 90% of patients presenting to Australian public hospital emergency departments will be admitted, transferred or discharged within four hours.</p>			

<b>Project Title</b>	<b>Incidence and burden of childhood injury in Australia</b>		
<b>Principal Investigator</b>	Dr Rebecca Mitchell		
<b>Institution</b>	University of New South Wales		
<b>Start Date</b>	1 December 2013	<b>Finish Date</b>	31 December 2016
<p>The total burden and causes of paediatric injury in Australia by severe injury are not clear, and a more accurate "snapshot" of the incidence and characteristics of severe injury and related follow-up care in Australian children is especially needed. Several factors can influence survival following injury, including type and level of trauma centre. These factors need to be examined, so they can be taken into account in the provision and coordination of trauma care for injured children. Overall, this research will better inform injury prevention strategies, research priorities, trauma system design, health services planning and resource needs.</p>			

**Note:** minor amendments have been made to summaries to comply with Department of Health WA *Health Writing Style Guide*



Delivering a **Healthy WA**