

## Human Research Ethics Committee

Project Summaries for Approved Proposals

April to June 2013 Quarter

Delivering a Healthy WA

## Project summaries for proposals approved by the Department of Health Human Research Ethics Committee – April to June 2013 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. It contains lay description/summaries available for the April to June 2013 quarter.

Project Title	Health policy makers' perceptions of the development and implementation of compulsory public health measures			
Principal Investigator	Dr Jackie Street			
Institution	University of Adelaide			
Start Date	1 January 2013	Finish Date	31 December 2013	

The project aims to understand the nature of decision making processes of policy advisors, policy makers and politicians used in the introduction and implementation of compulsory public health measures in Australia through a structured review of the relevant literature and interviews. Examples of such compulsory measures include bicycle helmet laws, smoking bans and vaccination of health care workers.

The researchers plan to conduct in-depth interviews with up to 20 participants selected from those policy makers, policy advisors and politicians who are influential in developing and implementing public health policy, potentially including compulsory measures. Participants will include public servants in key roles in the public service and State or National politicians, with a range of experience and expertise in the development and implementation of compulsory policy measures.

Project Title	Long term outcomes of recombinant growth hormone therapy			
Principal Investigator	Dr Amanda Langridge			
Institution	Telethon Institute for Child Health Research			
Start Date	14 March 2013	14 March 2013Finish Date31 December 2013		

Recombinant human growth hormone (rhGH) has been used to treat a range of conditions including congenital growth hormone (GH) deficiency, acquired GH deficiency, chronic renal insufficiency, cranial lesions or irradiation, hypoglycaemia, paediatric syndromes (e.g. Turner's Syndrome, Prader-Willi, etc), and idiopathic short stature (ISS). While traditionally rhGH therapies were only used to treat GH deficiencies, this has now increased to include conditions, such as intrauterine growth retardation, where the child may not actually be GH deficient.

To date, most studies conducted have been post-marketing surveillance undertaken by pharmaceutical companies. These usually includes a smaller number of participants, for a limited period of time and only include participants that meet strict inclusion / exclusion criteria, such as being GH deficient. For this reason, it is of upmost importance that studies investigate the short and longer term effects of GH therapy on the broader group of children receiving this therapy. The WA data linkage system and the KIGS/OZGrow database provide a unique opportunity for this project to examine the long term outcomes of recombinant growth hormone therapy.

Project Title	Defining appropriate use of troponin testing for diagnosis of acute coronary syndromes in primary care		
Principal Investigator	Dr Helen Wilcox		
Institution	University of Western Australia		
Start Date	1 December 2009	Finish Date	31 December 2013

A troponin test is a blood test for levels of protein released from damaged heart muscle. It is used in the diagnosis of acute coronary syndromes, otherwise known as heart attacks. Urgent treatment for patients with heart attacks is required to improve the chance of survival and of avoiding long term illness. If the test is ordered in a general practice, a result may not be available for many hours. During this time the patient may not be monitored for complications or this urgent treatment nor undergoing monitoring for complications.

This study will assess if patients who have a troponin test in general practice miss out on this urgent treatment or experience heart attack complications.

Project Title	Evaluating equitable management of acute coronary syndrome across regional Western Australia		
Principal Investigator	A/Prof Rachael Moorin		
Institution	Curtin University of Technology		
Start Date	1 May 2013 Finish Date 10 April 2017		

Coronary heart disease is the leading cause of death and ill-health in Australia. Acute Coronary Syndrome (ACS) contributed to approximately 80,000 hospitalisations and 10,000 deaths in 2009 across Australia. Positive outcomes for ACS patients are dependent on rapid response to symptoms, appropriate diagnostic measures and efficient medical interventions. It is thought that those from rural and remote areas may be disadvantaged since their access to medical facilities is often limited most notably by time and distance.

This study will assess the effects of access to services on diagnostic and treatment pathways for ACS and the effect on outcomes in WA.

Project Title	Analysis of services used and the costs of caring for people living with HIV/AIDS (PLWHA) in WA			
Principal Investigator	Dr Donna Mak			
Institution	Department of Health			
Start Date	1 July 2013	1 July 2013 Finish Date 1 January 2014		

The incidence of HIV in WA is rising. HIV clinicians report that this may be due to a rise in temporary visa holders entering WA from high-prevalence countries and a rise in incidence in heterosexual Australian-born men acquiring HIV overseas. These two groups may be more likely to present at more advanced stages of infection and as a result have higher costs of care due to hospitalization. Temporary visa holders do not have access to Medicare funded treatment and treatment is often provided by state funds.

This study aims to quantify these two subgroups and estimate the costs of caring for them in comparison with total costs for people living with HIV/AIDS in WA. The findings of this study will be used to inform policy and resource allocation in the state based on current requirements.

Project Title	Which are the most effective strategies for engaging with clinicians before and during the implementation of E-health initiatives?		
Principal Investigator	Ms Sophie Cramb		
Institution	PathWest		
Start Date	10 March 2013	Finish Date	10 May 2013

The project aims to identify which are the most effective methods for engaging with clinicians before and during the implementation of e-health initiatives. A literature review will be conducted to show that although clinical engagement is cited as paramount in successful e-health implementation, there is a gap in the research related to the methods which are most effective. A brief list of engagement methods will be identified from the literature.

An anonymous questionnaire will be formed using best methodological practice and distributed electronically to clinicians, IT managers and project managers / officers who have been involved in e-health initiatives. These individuals will be asked whether they have used the methods cited by the literature, which other methods they have used and which they found most effective and why.

Approximately, 160 people will be sent the questionnaire across a number of WA health organisations: Health Information Network, Pathwest, Sir Charles Gairdner Hospital, Fremantle Hospital, Swan Districts Hospital, Royal Perth Hospital, King Edward Memorial Hospital and Fiona Stanley Hospital. Outcomes expected include:

- a list of clinical engagement methods used in WA Health;
- a comparison of this against the recommended methods sited in the literature;
- an evaluation of the effectiveness of these methods
- recommendations if further e-health initiatives regarding which clinical engagement methods are to be used.

Project Title	Missing voices: communication difficulties after stroke and traumatic brain injury in Indigenous Australians - linked data component		
Principal Investigator	A/Prof Judith Katzenellenbogen		
Institution	Combined Universities Centre for Rural Health, UWA		
Start Date	1 July 2013	Finish Date	30 June 2015

Strokes and brain injuries are more common among Indigenous than non-Indigenous Australians, with strokes occurring on average at a much younger age in the Indigenous population. Both of these conditions are often complicated by long-term speech problems. However, almost nothing is known about such Acquired Communication Disorders (ACD) among Indigenous Australians.

This linked data study will use anonymous hospital records from all of WA to examine the occurrence of and interventions for ACD among Indigenous patients hospitalised for stroke or brain injury. This will form part of a larger project that aims to investigate and improve the detection of, and services provided for, Indigenous persons with ACD.

Project Title	An integrated national assessment of cervical cancer prevention, incidence and survival for Australian Aboriginal and Torres Strait Islander women: a data linkage study		
Principal Investigator	A/Prof Gail Garvey		
Institution	Menzies School of Health Research		
Start Date	1 March 2013	Finish Date	31 December 2016

Cervical cancer is much more common among Indigenous women than non-Indigenous women, however, little is known about their cervical screening participation or outcomes.

This study will use pap test registers and other data sources to compare screening participation and outcomes for Indigenous and non-Indigenous women, and investigate whether cervical cancer incidence has decreased for Indigenous women in recent years, as it has done for non-Indigenous women in Australia.

Project Title	The long term consequence of IVF on the offspring – a prospective cohort study using the Raine cohort as comparator – initial contact leading to recruitment		
Principal Investigator	Prof Roger Hart		
Institution	King Edward Memorial Hospital		
Start Date	1 April 2013	Finish Date	30 March 2018

In Australia one in 25 children are born resulting from in-vitro fertilisation (IVF) treatment - no data exists as to the long-term health of these children. This will be the first large scale study using long-term follow-up of children born as a result of IVF technology. It will compare their growth, development, metabolic, endocrine, psychological and respiratory parameters against a well-established longitudinal cohort. The Western Australia Pregnancy Cohort (Raine) study is a prospective cohort of pregnancy, childhood, late adolescence and young adulthood.

This study presents a unique opportunity in the relatively isolated and static population of WA to compare a cohort of children born as a result of IVF treatment. This well defined representative population of children born as a result of IVF technology in WA cannot be replicated in Australia or internationally.

Project Title	Health outcomes for older Indigenous Australians: a five year follow up study			
Principal Investigator	W/Prof Leon Flicker			
Institution	University of Western Australia			
Start Date	1 October 2010	1 October 2010 Finish Date 1 July 2013		

The research team completed a prevalence study of 363 Indigenous Australians in the Kimberley during 2004-2006, and documented high levels of dementia in people aged over 45 years (12.4%). Many chronic illnesses experienced by non-Indigenous older Australians (over 75 years) appear to be manifested at younger ages in the Indigenous population, including dementia, stroke, diabetes and cardiovascular disease. These illnesses lead to greater levels of disability and functional decline.

This project called the Kimberley Healthy Adults Project, aims to follow up the initial cohort five years later, including a new group of 45-50 year old Indigenous community members. A wider range of validated measures will be utilised to determine the prevalence and predictors of other 'aged care syndromes' such as falls, urinary incontinence, depression, disability, functional decline in older Indigenous Australians as well as dementia. The extent and causes of carer stress and burden and the level of health and community service usage will also be determined. In addition causes of death will be determined.

Project Title	Enhanced mortality database for estimating Indigenous life expectancy		
Principal Investigator	Dr Fadwa Al-Yaman		
Institution	Australian Institute of Health and Welfare		
Start Date	1 October 2012	Finish Date	31 August 2013

There is imperfect identification of Indigenous deaths in the key data sets used in preparing Indigenous life tables and mortality estimates. As a result, the true mortality characteristics of Indigenous Australians cannot be reliably measured.

The objective of the Enhanced Mortality Database project is to enhance death data through the linkage of several data sets that contain information on deaths and Indigenous identification. Indigenous status across the linked data sets will be compared to that on the mortality data set. A determination will be made, based on an appropriate algorithm, as to the number of deaths on the registered death data set with missing or incorrectly stated Indigenous identification that could be plausibly reclassified as Indigenous. This information will be used to create factors for adjusting death records to create a database containing enhanced Indigenous mortality information. The enhanced data will enable more accurate estimates of Indigenous mortality, including life expectancy estimates.

Project Title	Analysis of WA emergency department demand		
Principal Investigator	A/Prof David Whyatt		
Institution	University of Western Australia		
Start Date	19 September 2012Finish Date19 September 2014		

The project aims to map emergency department demand in WA. This will be compared to the provision of health services, including hospital, general practice and community services. The analysis will be used to inform coordinated clinical service planning by WA Health, Governing councils and Medicare locals.

Project Title	Does methadone maintenance treatment increase the risk of significant health problems in an older cohort?				
Principal Investigator	Dr Leigh Goggin				
Institution	Drug and Alcohol Office				
Start Date	3 June 2013	Finish Date	31 July 2015		

Given the projected increase of older adults in treatment for heroin addiction, it is critical to assess the health and mental health needs these individuals face, which may impinge upon their adherence to and success in drug and alcohol treatment. The lifestyle of regular drug users is typically defined as being more chaotic, and often demonstrating a high prevalence of adverse health behaviours and outcomes. Furthermore, these health outcomes are reported at higher rates for the cohort born in the late 1940's to the early 1960's. There's limited evidence on the direct health implications on this cohort and the long-term use of methadone. This area warrants further research given the growing proportion of ageing clients who remain in treatment for prolonged periods.

Project Title	Understanding an Aboriginal child's journey through paediatric ambulatory care in Western Australia				
Principal Investigator	Prof Karen Edmond				
Institution	Princess Margaret Hospital				
Start Date	1 July 2013	Finish Date	30 Jun	ne 2014	

It is a major concern that WA is unable to deliver quality hospital care to many Aboriginal children, especially children who are most disadvantaged and hardest to reach. Ambulatory care services aim to bring acute health care closer to communities and families. Ambulatory care is 'out of hospital' care including: outpatient services, specialist outreach services, community nursing, telehealth, hospital in the home, short stay facilities and emergency department services.

There are many high quality paediatric ambulatory services in Australia. However, there is little published information about how to improve inpatient or ambulatory care for the most disadvantaged Aboriginal children born preterm, children with complex developmental disabilities and the children who are "hardest to reach". The overall aim of this project is to improve ambulatory care for Aboriginal children in Western WA.

Project Title	Using data linkage to study the burden and impact of Clostridium difficile infection in Western Australia			
Principal Investigator	Prof Thomas Riley			
Institution	The University of Western Australia			
Start Date	1 July 2013	Finish Date	31 March 2014	

Clostridium difficile infection (CDI) is the most common cause of infectious diarrhoea in hospitals. In Australia, since mid-2011, rates of hospital-identified CDI have markedly increased. In order to better understand the burden, patient profile and management of CDI in WA, data on all cases diagnosed in WA hospitals between July 2011 and June 2012 will be analysed using data from the Hospital Morbidity Data System.

This study will review the 12 months preceding the infection to examine risk factors, and also the subsequent six months to examine patient outcomes (e.g. management, relapse, mortality, costs) associated with CDI.

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

