



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

Department of Health Western Australia Human Research Ethics Committee

Project Summaries for Approved Proposals

October to December 2019 Quarter

Project summaries for proposals approved by the Department of Health Human Research Ethics Committee – October to December 2019 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 October to December 2019 quarter.

Project Title	Sebaceous Carcinoma in Western Australia		
Principal Investigator	Dr Nathan Harvey		
Institution	PathWest Sir Charles Gairdner Hospital		
Start Date	1 October 2019	Finish Date	1 October 2020

Cutaneous sebaceous carcinoma is a rare type of skin cancer arising from sebaceous glands (a part of the hair follicle). Traditionally it is divided into extraocular and periocular types, the latter believed to derive from specialised sebaceous structures within the eyelid. This type of skin cancer has been associated with relatively aggressive clinical behaviour, with reported recurrence rates of approximately 30% and tumour-related mortality of approximately 20%. While extraocular tumours were initially thought to have a better outcome, more comprehensive studies demonstrated that tumours in these locations can also behave aggressively. Thus, patients with this type of cancer are typically treated aggressively, often involving potentially disfiguring surgery (particularly for tumours of the periocular region).

More recently, studies based on cancer registry data from the United States have suggested a changing picture. Rates of local lymph node metastasis are now approximately 1-2%, with an overall (all cause) 10-year survival approximately 80% of that of the age-matched population. In addition, there have been variable findings with regard to the relative behaviour of ocular versus extraocular tumours.

While sebaceous carcinoma is most commonly seen in Caucasian patients, there is some evidence that tumours in other ethnic groups may have a worse prognosis. To the knowledge of this project team, there has been no comprehensive evaluation of sebaceous carcinoma in the Western Australian population. The Western Australian Cancer Registry has gathered data on this tumour subtype over several decades and represents a valuable resource. This study aims to interrogate this database for the incidence and outcome of sebaceous carcinoma in Western Australia. In particular focus will be on changing trends over time, differences between ocular and extraocular tumours and differences between tumours of different histological grade. It is hoped that findings will help to inform appropriate management of this rare, but potentially aggressive, form of skin cancer.

Project Title	Identifying gaps in Hepatitis B screening and management in the Midwest region of Western Australia (WA), and Aboriginal and Vietnamese insights into their understanding of Chronic Hepatitis B.		
Principal Investigator	Dr Marisa Giles		
Institution	Geraldton Population Health Unit		
Start Date	12 December 2019	Finish Date	31 March 2021
<p>Chronic Hepatitis B (CHB) is a serious, preventable disease which results in a significant contribution to the burden of disease in Australia. Aboriginals and immigrants from areas of high endemicity such as Vietnam are at a higher risk of morbidity and mortality. Studies of CHB will identify gaps in prevention, diagnosis, and management and lead to improvements in outcomes.</p> <p>The objectives of this study are:</p> <ul style="list-style-type: none"> • to determine the knowledge of General Practitioners and their patients in the Midwest Region (Western Australia), particularly in high risk groups of Aboriginal and Vietnamese people, with regards to screening, diagnosis, and management of CHB; and • to improve the access and knowledge of at-risk communities with regard to CHB in the town of Carnarvon, Gascoyne district Midwest Region. 			

Project Title	Smoke Alert: tracking smoke complaints in the southwest of WA		
Principal Investigator	Dr Peter Franklin		
Institution	Department of Health		
Start Date	1 November 2019	Finish Date	31 May 2020
<p>Bushfires occur regularly in Western Australia. In some instances these fires can be catastrophic due to loss of property and, more importantly, human life. The frequency and intensity of bushfires are projected to increase due to changes in the climate. In most Australian states, including WA, prescribed, or planned, burns are part of a strategy for bushfire management. However, smoke from prescribed burns can drift over urban areas and can both create a nuisance and impact human health.</p> <p>Increased pollution from smoke plumes is not always captured on air quality monitors due to the sparse distribution of these in Perth and Southwest towns, where prescribed burns are mostly likely to have an impact. The Department of Biodiversity, Conservation and Attractions (DBCA) decide on when and where to do prescribed burns. The Department of Health (DOH) sits on a smoke management committee but has no role in the decision-making process for burns. However, the DOH receives complaints when smoke plumes from prescribed burns drift over Perth and other major urban centres. The DBCA also has a complaints line but neither organisation keeps adequate records of these complaints so there is little information on where they come from and how often they are received. For this study the DOH is trialling a method, a phone app, to try to better understand the impact of smoke from prescribed burns, at least in terms of nuisance. The current study is a feasibility study of the uptake and utility of the phone app.</p>			

Project Title	Modelling the Health and Crime Impacts of a Minimum Price on Alcohol for Western Australia		
Principal Investigator	Mr Colin Angus		
Institution	University of Sheffield, Sheffield UK, Department of Health Western Australia		
Start Date	18 October 2019	Finish Date	18 October 2022

In September 2017 during Budget Estimates, the Western Australian Minister for Health called for community consideration of a minimum price on alcohol to prevent alcohol-related harm and reduce pressure on the health system. In 2019, the Western Australian Government endorsed the final report of the Sustainable Health Review which included a recommendation to introduce a minimum price on alcohol.

The Western Australian Government (Mental Health Commission) has contracted the University of Sheffield to undertake a statistical modelling exercise to determine likely health and crime impacts at different price points of a minimum price on alcohol in Western Australia for the purpose of informing community discussion and Government considerations. Minimum unit pricing directly links price to alcohol content by setting a floor price below which a single unit of alcohol cannot be sold to consumers.

Project requirements include consumption and price paid for alcohol survey reports, aggregated Western Australian morbidity data, mortality data, health costs and crime offence data for the calendar years 2013, 2014, 2015 and 2016. The morbidity and mortality data are for the number of adult people that died or were hospitalised by 46 identified health conditions grouped by: age band (18-24, 25-34, 35-54, 55-89), sex (male/female) and socio economic status in Western Australia by quintile.

The model will be used to appraise the potential impact of a range of four to six minimum unit prices on alcohol consumption, consumers' spending on alcohol, the revenue from alcohol sales as well as estimating how alcohol-related hospital admissions, deaths and crimes and associated costs might change. The project will also explore how these impacts vary across the population in terms of socioeconomic status and drinker level, i.e. whether minimum unit price widens or narrows inequalities in health and whether it has a greater or lesser impact on moderate, rather than heavy drinkers.

Project Title	Trends in the perinatal diagnosis of congenital heart defects in Western Australia: 2004-2017		
Principal Investigator	Dr Shin Lee		
Institution	King Edward Memorial Hospital, Perth Children's Hospital, Department of Health		
Start Date	5 December 2019	Finish Date	30 April 2022

Congenital heart defects (CHDs) have an estimated incidence of 1% of live births and may be associated with significant morbidity and mortality. Prenatal diagnosis of CHDs has been found to reduce perinatal mortality in some conditions but not others, and assist in the provision of appropriate prenatal counselling and pregnancy management. The prenatal screening and ascertainment of prevalence for CHDs is challenging. Despite a consensus recommendation for CHD screening during the mid-pregnancy fetal anatomy ultrasound survey, the detection rates for CHD vary widely (between 30 to 50%). Furthermore, the variation in nomenclature and classification systems used in prevalence studies, such as the International Classification of Disease, 9th revision (ICD-9) and the Metropolitan Atlanta Congenital Defects Program, further contribute to the wide variance in reported prevalence rates of CHDs.

The primary aim of this study is to review the temporal changes in the perinatal detection and pregnancy outcomes of infants with CHDs from 2004-2016, in the state of Western Australia. The other objective of this study is to assess the diagnostic accuracy of the ICD-9 coding of clinically significant congenital cardiac lesions.

Project Title	Multicentre randomised controlled trial: caregiver, patient, and system outcomes from a program supporting informal caregivers of older people discharged home from hospital		
Principal Investigator	A/Professor Christine Toyne		
Institution	Curtin University		
Start Date	28 November 2019	Finish Date	31 December 2028

Supporting home caregiving for older people in failing health is now a critical issue in Australia. Hospital admission of an older person receiving care from family or friends presents an opportunity to identify and address the support needs of these carer's, and to build their skills to continue to do this independently. This study will trial the Further Enabling Care at Home (FECH) program, which was previously found to benefit carer's of older people returning home from hospital in terms of reduced carer strain and distress and increased preparedness to care. The program is delivered by specially prepared nurses over the phone, after the discharge, and is designed to guide the carer to identify and rate their support needs, then address the most pressing of these needs via a problem solving approach. The intent is to build the capacity of carer's over the 6-month program so that they can then identify and address their support needs without FECH nurse help.

Because caregiving preparedness was previously improved by the program, it is arguable that improvements in care, and thus in care recipients' independence and symptoms, may result, with subsequent reductions in care recipients' needs for health services and residential aged care. Similarly, improved health related quality of life (HRQoL) may occur in carer's through completion of the FECH program, thus reducing their use of health services. These reductions in service use, and therefore in costs, could then help to justify widespread program implementation.

Aims of this study are to (a) measure impacts from the FECH program on carer's (HRQoL, self-efficacy, preparedness, strain, distress), patients (symptom distress, independence), and the use and costs of health and residential care services and (b) explore and describe how caregiving is influenced by the program. The randomised controlled trial will be conducted in Queensland and Western Australia, involving three hospitals.

Project Title	Identifying genetic risk factors for cardiovascular disease in extended pedigrees in the Busselton Health Study		
Principal Investigator	Professor Eric Moses		
Institution	Department of Health		
Start Date	18 November 2019	Finish Date	31 December 2021
<p>Cardiovascular disease (CVD) is the result of complex interactions between genetic, host and environmental factors. Although widely studied using genome wide association, most of the genes involved in the determination of CVD susceptibility remain unknown.</p> <p>The aim of this project is to identify genes that are associated with CVD and associated CVD risk factors in participants 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, blood measures, and questionnaire data). Mortality and hospital morbidity data collected from the Department of Health Western Australia will be used to define CVD events.</p> <p>This project will use these data to determine the extent to which CVD and its risk factors are due to our genes. We will also seek to determine whether CVD and its associated risk factors share common genetic components. Millions of genetic variants will then be statistically tested to ascertain those contributing significantly to CVD risk within this cohort. We will also use these genetic variants to develop a genetic risk score for CVD, allowing us to identify individuals at increased risk of CVD due to their genes. Results from this project will help to identify people at increased risk of CVD providing them with the opportunity to change their behaviours or receive treatment earlier. This will help reduce the impact of CVD in Australia.</p>			

Project Title	Describing congenital heart defects in Western Australia: 1980-2016.		
Principal Investigator	Dr Michele Hansen		
Institution	Telethon Kids Institute, Department of Health		
Start Date	13 November 2019	Finish Date	31 May 2021
<p>Congenital heart defects (CHD) occur when the heart or adjacent intrathoracic great blood vessels do not develop normally before birth. They are among the most common types of birth defect and a major cause of infant and childhood illness and death. This descriptive population-based study will examine the prevalence, causes (where known), and associated defects and age at first diagnosis of infants diagnosed with CHD in Western Australia over a 36-year period. The study population will comprise all infants born in Western Australia between 1980 and 2016 diagnosed with a congenital heart defect and notified to the WA Register of Developmental Anomalies.</p> <p>Specific objectives:</p> <ol style="list-style-type: none"> 1. Describe the prevalence of CHD in WA from 1980 to 2016. 2. Examine diagnostic characteristics of affected children including birth outcome (live born, stillborn, termination), association with other congenital anomalies, age at diagnosis and cause where known. 3. Investigate trends in prevalence for all vs severe CHD, causal groups, in metro vs rural and remote areas, for births to Aboriginal vs non-Aboriginal mothers and for subtypes of CHD. 			

Project Title	Incidence of Ocular Melanoma in Australia: 1982-2015		
Principal Investigator	Dr Elin Gray		
Institution	Department of Health, Edith Cowan University, Lions Eye Institute		
Start Date	5 December 2019	Finish Date	23 November 2020
<p>Ocular Melanoma (OM) is a rare disease consisting of uveal melanoma (UM) and conjunctival melanoma (CJM). UM is the second most common melanoma after cutaneous, with CJM having lower incidence than all other types of melanoma. Similar to cutaneous melanoma, UM and CJM incidence in Australia is high with a reported rate of 9.8 (8.3 choroid, 0.7 ciliary body, 0.8 iris) and 0.8 per million per year respectively. However, the most recent update to the Australian incidence of UM was published in 2003 using data extracted from 1990-1998 International Journal of Cancer. In this regard, an updated report on the status of OM in the Australian population is warranted.</p> <p>The aim of this project is to obtain OM cancer data from each cancer registry in Australia to provide updated incidence and mortality information for the Australian population.</p>			

Project Title	Accuracy and cost-effectiveness of technology-assisted dietary assessment		
Principal Investigator	A/Professor Deborah Kerr		
Institution	Department of Health		
Start Date	13 December 2019	Finish Date	20 June 2022
<p>This project will compare leading methods for technology-assisted dietary assessment. Excessive cost and questionable accuracy limit the routine use of dietary assessment and undermine decision making in Australia. Three technology methods of assessing diet will be compared with the current standard recall method used in population surveys. The approach will confirm if the use of food images and automated methods provide new approaches to improve accuracy and consumer acceptability. The outcomes of this project will lead to more accurate and acceptable methods to assess dietary intake to inform effective government decision making about the types, amounts and drivers of food consumption of the population.</p> <p>Benefits and Impact Statement: The project will identify key factors associated with accuracy, cost and consumer acceptance of methods to assess diet for population surveillance. Current methods are resource intensive and have shown a decline in accuracy and consumer acceptability over time, for reasons yet to be fully explored. Providing more reliable and acceptable technology methods using images will lead to improvements in dietary monitoring and surveillance. Accurate and contemporary dietary intake is useful for food and nutrition policy including, health, education, agriculture and trade. Ultimately this will better inform decision making for researchers, policy makers and practitioners in Australia, potentially leading to more regular population surveillance.</p>			

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