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

Department of Health Western Australia Human Research Ethics Committee

Project Summaries for Approved Proposals

January to March 2021 Quarter

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Project summaries for proposals approved by the Department of Health Human Research Ethics Committee – January to March 2021 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 January to March 2021 quarter.

Project Title	RGS 4462. Risk assessment of Legionella pneumophila in cooling towers in Western Australia		
Principal Investigator	Dr Abby Potter		
Institution	Department of Health		
Start Date	19 January 2021	**Finish Date**	1 February 2022

Legionnaires' Disease is a respiratory illness caused by the water-borne bacteria *Legionella pneumophila*. Research from other jurisdictions within Australia, and overseas, highlights the role that cooling towers play as a source of infection for a cluster or outbreak of Legionella, particularly in the metropolitan area. Research of this nature has not yet been undertaken in Western Australia (WA). Given the increasing trend of Legionella cases within the State, this research aims to map the location of cooling towers in five local government regions and determine whether there is a correlation with case notifications of Legionnaires' Disease to the Department of Health in WA. The request for data will play an essential role in ensuring the mapping component of this research can be undertaken.

In other states of Australia, legislation is in place to regulate potential sources of risk to public health, associated with Legionella. In WA, a regulation review is currently underway to determine how the public health risk associated with cooling towers can be best managed and regulated. The mapping of cases and correlation with cooling tower locations will play an important role in defining the risk in WA, which will in turn play an important role in informing the regulation review.

The broader project, of which this study forms a part, will also involve the development and evaluation of a risk assessment tool for cooling towers, to be used by Environmental Health Officers. This will assist Local Government in fulfilling their regulatory responsibilities under the new *Public Health Act 2016*.

Project Title	RGS 4469. STaR-Link: National collection of cancer data on stage, treatment and recurrence (STaR) – Phase 2 data linkage		
Principal Investigator	Dr Alan Woods		
Institution	Cancer Australia		
Start Date	10 February 2021	**Finish Date**	4 January 2024

Reporting national data on cancer type, stage at diagnosis, treatments applied and patient outcomes will provide a better understanding of variations in cancer diagnosis, treatments and outcomes at a population-level. This evidence base will assist in directing cancer control efforts to address unwarranted variations to improve cancer outcomes.

This project seeks to link information on cancer incidence, stage at diagnosis, treatments, and survival/mortality. The proposed analysis will examine a cohort of people diagnosed with one of the five highest incidence cancer types (female breast, lung, prostate, colorectal, melanoma) in 2011.

This project will inform future cancer control efforts to reduce variations in cancer outcomes across sociodemographic groups in Australia by using linked data to understand relationships between cancer stage at diagnosis, treatments and outcomes across different population groups. Project learnings will also be used to inform the ongoing analysis and reporting of linked cancer data over time in future projects.

Project Title	RGS 4161. Longitudinal study of prognostic biomarkers for melanoma		
Principal Investigator	Dr Elin Gray		
Institution	Edith Cowan University		
Start Date	23 February 2021	**Finish Date**	21 November 2023

“Liquid biopsy” is a promising concept that encompasses a range of tests that can be performed from blood and other body fluids to provide tumour specific information. It promises the early detection of cancer, prognostication of those at high risk of relapse, detection of minimal residual disease, guidance for therapy selection and treatment response monitoring.

To examine the clinical validity of ‘liquid biopsy’ markers, this project aims to assess the prognostic significance of autoantibodies (AAbs) and circulating tumour cells (CTCs) in a patient’s blood sample. As part of an earlier project in 2016, blood samples were collected from melanoma patients and analysed for biomarkers. The results were then related to clinical data provided by the patient’s treating clinician.

However, the cohort of patients were recruited and analysed for CTCs and AAbs more than five years ago when their primary lesions were diagnosed. It is likely that disease in some of these patients has progressed or the patient has died since recruitment. These participants may not have returned to their original treating clinician when their disease progressed and were not followed up by the project. Without complete mortality and progression data on all of the patient cohort, the research team is limited in its ability to assess the long-term prognostic validity of biomarkers in relation to patient disease progression and overall survival. Therefore, to determine patient outcomes the study will again request unlinked mortality and progression data from the WA Cancer Registry and repeat the process undertaken in 2016.

Project Title	RGS 4435. The impact of COVID-19 pandemic on emergency department presentations, hospitalisations, all-cause mortality and cancer notifications in Western Australia.		
Principal Investigator	Professor Rachael Moorin		
Institution	Curtin University		
Start Date	23 February 2021	**Finish Date**	31 December 2022

The COVID-19 pandemic has had an effect in WA directly, through requirements for social distancing, restrictions on business operations and changes such as loss of employment or adaptive strategies like working from home. Recent international literature has indicated that the COVID-19 pandemic has also had an indirect negative impact on care relating to acute and chronic medical conditions. This project will analyse changes to emergency departments and hospital admissions during 2020 and compare them with expected trends using historical data, to identify changes in health-seeking behaviour and suggest strategies that may be required for increased follow-up of affected groups within the community. This project will also assess trends relating to all-cause mortality, as there may be planning implications from any changes occurring during 2020 as a result of the COVID-19 pandemic.

Project Title	RGS 4505. Do major spinal and hip surgeries improve the lives of children with severe disability and their families?		
Principal Investigator	Associate Professor Jenny Downs		
Institution	Telethon Kids Institute		
Start Date	2 March 2021	**Finish Date**	2 March 2024

Over 5,000 children are born each year in Australia who grow up with intellectual disability (ID). Population-based research for this group is difficult due to the lack of systematically collected data specific to ID over a long time. Intellectual Disability Exploring Answers (IDEA) is a population-based database that was established by the study team for children with ID born in WA. It is unique in Australia for capturing all children with an ID diagnosis. The data shows that, compared to unaffected children, children with ID live with many comorbid health conditions, are up to 10 times more likely to be hospitalised and have a nine-fold increase in mortality usually from respiratory causes.

In severe ID, epilepsy is highly prevalent. Feeding difficulties and gastro-oesophageal reflux commonly occur. These may result in poor growth, aspiration of food and fluids into the lungs and recurrent chest infections. Those with severe ID are often unable to walk conferring additional vulnerability to musculoskeletal complications including progressive spinal deformity, hip dysplasia and dislocation. These deformities which affect body posture, weight distribution and movement are associated with the development of progressive restrictive lung disease which exacerbate the propensity to recurrent chest infections.

Previously, the team investigated the use of gastrostomy and health outcomes for children with ID who have undergone gastrostomy insertion. The findings revealed that gastrostomy insertion was associated with a reduction in all-cause hospital admissions, possibly because of better nutritional status. Epilepsy-related hospitalisations also decreased, possibly because of more reliable delivery of medications. However, the high frequency of admissions for lower respiratory tract infections did not decrease suggesting that gastrostomy does not protect respiratory health.

This project will assess different outcomes within that same data set and explore health outcomes (hospitalisations) following complex orthopaedic surgeries.

Project Title	RGS 3451. Establishment of a Western Australian Congenital Heart Disease database to evaluate trends in the incidence of congenital health disease in Western Australia		
Principal Investigator	Dr Bradley McDonald		
Institution	Perth Children's Hospital		
Start Date	16 March 2021	**Finish Date**	1 January 2023

Congenital Heart disease (CHD) is the most common birth defect, affecting 4-50 per 1000 live births worldwide. There have been few extensive studies reviewing epidemiology of CHD and no further studies have been performed Australia-wide. The Perth Children's Hospital (formerly Princess Margaret Hospital for Children) is in a unique and privileged position to enable complete data capture, given that nearly all diagnoses of CHD in WA are channelled through the cardiology department. The aim of the study is to evaluate trends of CHD in WA and elucidate the changing incidence of specific aetiologies of CHD over time through the creation of a CHD database.

This is a retrospective observational study that will document echocardiographic diagnosis of CHD since 2003 in association with epidemiological and medical record data. Secondary aims include documenting associated co-morbidities in patients with various forms of CHD, assessing demographic details and reviewing trends in CHD in WA. This will allow for increased awareness of the changing climate of CHD and may help to guide future service delivery in WA.

Project Title	4359. First 600 COVID-19 cases in Western Australia: public health response effectiveness of contact tracing and restrictions in WA		
Principal Investigator	Dr Benjamin Scalley		
Institution	Department of Health		
Start Date	17 March 2021	**Finish Date**	17 March 2024

Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) is the infective agent that causes coronavirus disease 2019 (COVID-19). SARS-CoV-2 is a novel coronavirus that was first identified in humans in Wuhan, China, in December 2019. The predominant modes of human-to-human transmission is by droplets and fomites from an infected person. The World Health Organisation declared an outbreak of COVID-19 on 30 January 2020, before declaring a worldwide pandemic on 11 February 2020.

Other regions around the world who were affected by COVID-19 earlier than Australia (such as Singapore and China) showed control of COVID-19 by a combination of strategies. These included movement restrictions, social distancing, hygiene practices and intensive public health follow-up of cases and contacts. During the COVID-19 pandemic, Australia and WA implemented some measures aimed at slowing the spread of COVID-19 into and within the country and state. These measures also prepared healthcare services and laboratories for a targeted response. This study investigates the impact of restrictions put in place by the Australian and WA Government, on the epidemiology of the first wave of COVID-19 in WA and assesses the measures of public health performance.

Project Title	Health service utilisation and long-term outcomes from Kawasaki disease, using the Western Australian Linked Data		
Principal Investigator	Dr Pamela Bradshaw		
Institution	The University of Western Australia		
Start Date	30 March 2021	**Finish Date**	31 July 2023

Advances in surgery, anaesthetics, medical therapy and technology over previous decades have improved survival for children born with a heart defect (congenital heart disease). There are now more adults than children living with congenital heart disease in Australia.

In addition to conditions affecting the heart and major blood vessels from birth (congenital heart disease), children may suffer damage to the heart in childhood from infections, such as rheumatic fever, and from inflammatory conditions, including Kawasaki disease. Kawasaki disease affects mostly babies and young children, but little is known about the cause of the disease, nor what the long-term outcomes might be. Children are unwell and suffer signs of an infection with fever and rash. There is also inflammation of the blood vessels which, in some cases, leads to damage to the walls of one or more of the coronary arteries which supply blood to the heart.

While the few long-term studies of Kawasaki disease have found generally good survival, patients with large or persistent coronary artery damage (aneurysm) are more likely to suffer early death or cardiovascular disease. The use of health services after hospital discharge by patients after being treated in hospital discharge from hospital Kawasaki disease is largely unknown. A previous WA study suggests an increased incidence of infections and immune-related conditions in children with Kawasaki disease.

This study will be the first long-term follow-up of Australian children with Kawasaki disease. Researchers from the former Princess Margaret Hospital used the linked data from 1979 to 2009 to estimate that 170-180 children are admitted to hospitals across Australia each year with Kawasaki disease. The WA cases, and the additional cases admitted to hospital with Kawasaki disease since 2009, will be compared to control subjects (without serious heart disease) to determine whether hospital admissions and emergency department attendances are more frequent among children and adults with a history of Kawasaki disease, together with the reason for admission or emergency department attendance.

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