Government of Western Australia
Department of Health

Human Research Ethics Committee

Project Summaries for Approved Proposals

October to December 2013 Quarter

Project summaries for proposals approved by the Department of Health Human Research Ethics Committee – October to December 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 (DOH HREC). It contains lay description/summaries available for the October to December 2013 quarter.

Project Title	**National survey of high impact psychosis**		
Principal Investigator	Professor Vera Morgan		
Institution	The University of Western Australia		
Start Date	1 October 2010	**Finish Date**	31 December 2014

This project features the Survey of High Impact Psychosis (SHIP) and is being conducted in two stages: Stage 1, which involves gathering data from participants, and Stage 2, which involves gathering data from Department of Health data collections. SHIP Stage 1 has been completed. SHIP Stage 2 is in progress and involves linking Department of Health data collections for Stage 1 participants in Western Australia.

<u>SHIP Stage 1: the cross-sectional survey</u>

In 2010 this survey, which is Australia's second national survey of psychotic illness, was conducted in seven sites across Australia. The Western Australian site was in Perth’s South Metropolitan mental health service and covered Fremantle, Rockingham, Kwinana and Peel mental health services (South Metro SHIP). There were 393 people who gave consent to participate in the survey and were interviewed. In 2012, an extension of this survey was undertaken in Perth’s North Metropolitan mental health service (North Metro SHIP) with 250 people interviewed. The SHIP interview schedule included modules on psychopathology, substance use, service utilisation, medication use, education, employment and physical health. The survey data has enabled the project team to determine the prevalence of psychosis and to describe the profile of people with psychotic illness.

<u>SHIP Stage 2: the collection of longitudinal physical and psychiatric morbidity data and mortality data stored on the Western Australian linked health registers for consenting survey participants in Western Australia.</u>

As part of the consenting process, SHIP participants were asked specifically to "allow this survey to review my health outcomes via my case notes and State Health Services Research Linked Databases". Of the 643 people interviewed in South and North Metro SHIP, 622 gave written, informed consent to access their information. Register data will be accessed for the people who gave consent. The data increases the interview and assessment data collected in Stage 1, and provides a full history of physical and psychiatric morbidity prior to interview, as well as, any morbidity and mortality, including cause of death, in the period since interview.

Project Title	**CONCORD-2 Global surveillance of cancer survival**		
Principal Investigator	Professor Michel Coleman		
Institution	London School of Hygiene and Tropical Medicine		
Start Date	1 May 2012	**Finish Date**	31 December 2016

Cancer survival varies widely around the world. Of 12.7 million cancer patients diagnosed in 2008, 56% occurred in low and middle income countries. The number is expected to rise substantially by 2030, especially in poorer countries. The Union for International Cancer Control established 11 goals for 2020 in the World Cancer Declaration, including "there will be major improvements in cancer survival [rates] in all countries". Evaluation of progress toward these goals is required, but currently no mechanism exists to do this.

Aims:

1) to initiate systemic global surveillance of survival trends for 10 common cancers from 1995 to 2009; and 2) to create a global database for reporting cancer survival trends. This will involve: examining the causes of inequalities in survival, estimating the proportion of patients who are cured, the numbers of survivors and the numbers of avoidable premature detahs, and to contribute to national and global policy for cancer control.

Survival provides one measure of progress in cancer control. Comparisons of incidence, survival and mortality have been published for benchmarking breast, lung, colorectal and ovarian cancers as part of the International Benchmarking Study for developed countries but not worldwide. Where possible, incidence, survival and mortality will be compared for all the countries and regions participating in CONCORD-2, to help inform interpretation of the survival comparisons. The WA Cancer Registry will be one of the participating registries.

Project Title	**Investigating rising demand for emergency healthcare by older age groups**		
Principal Investigator	Doctor Judy Lowthian		
Institution	Monash University		
Start Date	9 October 2013	**Finish Date**	30 September 2014

Demand for emergency healthcare is a world-wide problem, placing stress on health systems. The volume and rates of emergency healthcare use in Melbourne continue to increase beyond that expected from population changes. The greatest increase in use of Emergency Departments (EDs) is by older age groups. Older people also use EDs more frequently than younger people. This is predicted to continue with population ageing. This project will analyse older people's use of EDs in Perth to determine whether the trends are similar to Melbourne's, and to determine what factors contribute to this rise in demand by older people.

Project Title	**Today's lung cancer risk in WA miners: using the power of linked data**		
Principal Investigator	Winthrop Professor Lin Fritschi		
Institution	The University of Western Australia		
Start Date	1 October 2013	**Finish Date**	31 December 2014
Working in mines has been associated with an increased risk of lung cancer, but there is no recent evaluation of the risk in Western Australian mines. Moreover, exposure to diesel engine exhaust is a major concern for lung cancer. This project will study the risks of lung cancer among Western Australian miners, with special attention to women and people who have never smoked before. The project will also identify the main determinants of the risk, such as type of mine, location in the mine (underground or surface) or job type. This information will inform policy and practice directed at making mine work safer.			

Project Title	**Influenza vaccination in pregnant women: a cohort study to assess vaccine uptake, effectiveness and impact on birth outcomes in Western Australia**		
Principal Investigator	Doctor Paul Effler		
Institution	Department of Health		
Start Date	1 December 2013	**Finish Date**	31 December 2016
Pregnant women have recently been identified by the World Health Organisation as the first priority for seasonal influenza vaccination campaigns. The National Immunisation Program provides influenza vaccine to pregnant women in Australia. While it is well accepted that vaccinating pregnant women for influenza can prevent infection in mothers, there have been fewer investigations into the ability of vaccinating pregnant women to prevent infection in newborn infants. Further, new research suggests that influenza vaccination may have a role in preventing preterm and small-for-gestational age births. While some studies support this approach, an evaluation of this strategy has not yet been conducted in Western Australia or anywhere else in Australia. This study will be used to assess benefits to infants by vaccinating mothers for influenza.			

Project Title	**Modelling linked population data to understand outcomes for children of incarcerated mothers and the role of the prison environment to reduce negative social and economic impacts**		
Principal Investigator	Professor Leonie Segal		
Institution	The University of South Australia		
Start Date	1 January 2014	**Finish Date**	31 December 2017
There is currently no routine collection of population level data on children whose mother is imprisoned during their childhood, and as such this population's service needs have not been clearly established. The proposed project will identify the number of Western Australian children who are affected by the incarceration of their mother, describe their characteristics and measure their outcomes in a number of key areas including health, education, juvenile justice and child protection. Predictive modeling and econometrics will then be used to investigate whether certain characteristics or circumstances predict better or worse outcomes for children. The associated cost implications will also be examined.			

Project Title	**St John Ambulance: infrastructure linkage**		
Principal Investigator	Professor Ian Jacobs		
Institution	St John Ambulance WA		
Start Date	13 November 2013	**Finish Date**	13 November 2017
Up to 2005, St John Ambulance records were linked to hospital, emergency and death records and these links were used in studies on cardiac arrest. This project will involve updating these links and expanding the linkage to include a wider range of data sources, in particular road crash (Main Roads), third party insurance and trauma registry records. This will enable a wider range of projects to be undertaken, to explore the progression from trauma response to treatment, rehabilitation and outcome.			

Project Title	**The relationship between diet and educational outcomes in a cohort of Western Australian children**		
Principal Investigator	Professor Wendy Oddy		
Institution	Telethon Institute for Child Health Research		
Start Date	1 January 2014	**Finish Date**	31 December 2015
There is growing body of evidence that suggests nutrition plays a role in children’s brain development, which in turn influences the learning, thinking and memory of the children and consequently their academic performance. This project aims to investigate the relationships between dietary intake during childhood and adolescence, and educational performance in Western Australian children up to 17 years, and to contribute to a growing body of knowledge concerning diet and educational outcome.			

Project Title	**Evaluation of the Aboriginal Maternity Group Practice Program (AMGPP) in the South Metropolitan Health Service**		
Principal Investigator	Doctor Christina Bertilone		
Institution	South Metropolitan Public Health Unit		
Start Date	11 December 2013	**Finish Date**	31 December 2014

This project aims to evaluate how effective the Aboriginal Maternity Group Practice Program (AMGPP) has been in helping Aboriginal women access maternity services in south metropolitan Perth from 1 July 2011 to 30 June 2013. The AMGPP is a program which is managed by the South Metropolitan Public Health Unit using funds obtained from the Council of Australian Governments. The program uses Aboriginal grandmothers and Aboriginal health officers to link pregnant Aboriginal women in with existing antenatal services. They operate out of five localities which are either physical sites or local organisations – Nidjalla Waangan Mia in Mandurah, Moorditj Koort in Medina, Boodjara Yorgas Family Care Program, Bentley Armadale Medicare Local and Fremantle Medicare Local. These five localities work with midwives from five local maternity hospitals at Peel Health Campus, Rockingham General Hospital, Armadale Hospital, Bentley Hospital and Kaleeya Hospital. Each of the five “sites” commenced at different times throughout 2009 and 2010 and work semi autonomously. This research will evaluate various aspects of the program as a whole.

The implementation phase of the program will be discussed and important documents related to this assessed. Women’s satisfaction with the program will be evaluated – this may be done through a written questionnaire, individual interviews or focus groups, if possible. AMGPP staff will be interviewed to assess the processes, strengths and weaknesses of the program. A validated tool will be used to assess the cultural competence of the program. The opinions of key stakeholders will be sought by way of a questionnaire.

The types of activities at each of the AMGPP sites will be described. Key pregnancy, post pregnancy and baby outcomes will be assessed and compared between women who attended the program and those that did not, to see if there are any differences, by means of a case-control study.

The program’s effectiveness will be assessed and recommendations made.

Project Title	**Life expectancy in cerebral palsy to the sixth decade**		
Principal Investigator	Associate Professor Eve Blair		
Institution	Telethon Institute for Child Health Research		
Start Date	1 January 2014	**Finish Date**	31 December 2014

The aim of this project is to extend a previous study of life expectancy in Western Australians with cerebral palsy (CP) from 41 birth cohorts (1956 to 1997) to 54 birth cohorts (1956 to 2010).

Justification: CP is an umbrella term for widely varying conditions provided they include a motor disorder of cerebral origin. The duration of life is correspondingly variable. Families, government and medical insurers need to predict the likely duration of life, particularly of those most severely impaired, in order to make arrangements for the provision of adequate care for the life span. In 1997, WARDA-CP was linked to the National Death Index for registrants born between 1956 and 1994 to identify those that had died by 1 June 1997. The results were published in 2001. In that study the oldest registrants were about 40 years old and few aged more than 30 years of whom very few had severe disability. Although almost half of those with severe disability had died before 20 years of age, their mortality appeared to decrease significantly thereafter. However, this observation was based on limited data so the previous study could provide little information about continued life expectancy for subjects with severe CP who had survived their teenage years.

Project Title	**Rare and emerging subtypes of under-researched cancers epidemiology studies (RESOURCES Program)**		
Principal Investigator	Professor Graham Giles		
Institution	Cancer Council Victoria		
Start Date	1 January 2010	**Finish Date**	30 December 2016

The Resources Program consists of four epidemiological case-control studies which focus on the causes of less common cancers including multiple myeloma, kidney cancer, aggressive prostate cancer and others. They are based at the Cancer Council in Victoria. The study design requires that both positive and negative reports of cancer and deaths within families are verified in the Australian Cancer Database (ACD) and National Death Index.

This project will contribute to the identiifcation of lifestyle exposures that may be associated with the development of these less common cancers, some of these exposures are potentially modifiable. These findings may assist in preventing the development of some cancers. The studies also have the potential to identify high risk genes or combinations of genes that may increase risk of developing cancer or may enable better targeting of treatment.

Project Title	**National familial hypercholesterolemia registry**		
Principal Investigator	Professor Gerald Watts		
Institution	The University of Western Australia		
Start Date	1 January 2014	**Finish Date**	11 December 2017

This project will establish a National Familial Hypercholesterolemia (FH) Registry collating the relevant personal, clinical and genetic data on Australians.

The aims of the National Registry for FH are to:

- facilitate service planning by analyses and reporting of data collected by the Registry on prevalence, geographical distribution, genetic variants associated with disease, clinical features, clinical management and patient outcomes;
- enable research by providing aggregate, de-identified data to research entities;
- facilitate identification and recruitment of eligible volunteers for clinical trials; and
- promulgate new knowledge to inform best practice and care services.

The National FH Registry will be a clinical enabling tool to benefit individuals with FH and their family members. The ultimate aim of the registry is to enhance the delivery of clinical services. It is not a formal research project.

The FH Registry is a multicentre collaboration through the FH Australasia Network (Australian Atherosclerosis Society) and a Principal Investigator from each state/centre will be involved. The objectives, aims and data requirements for the registry have been developed in consultation with members of the FH Australasia Network. The National FH Registry will provide a database of all Australian families with FH which is interoperable and compatible with the infrastructure and aims of localised data collections on FH patients. A National Advisory Board will be established and will provide oversight on the governance of the registry.

All patients will be allocated a unique identifier and the database constructed in such a way that the workgroups in each jurisdiction will only be able to visualize and have access to the data of their own patients. Only the national curator will have administrator privileges and hence access to patient data from all jurisdictions, including patients' personal information.

Patients will be registered by clinical service providers through existing jurisdictional clinical services. In addition to the database, an online patient registration tool will be developed to link to each database enabling patients to be actively involved in registering their details.

Project Title	**Evaluation of the southern inland health initiative navigator program**		
Principal Investigator	Associate Professor David Whyatt		
Institution	The University of Western Australia		
Start Date	1 January 2014	**Finish Date**	31 December 2016
The Western Australian Country Health Service (WACHS) has developed a comprehensive chronic conditions service coordination model, provisionally called the Health Navigator Program. The initial priority conditions to be targeted through the Health Navigator program are diabetes, chronic obstructive pulmonary disease and congestive cardiac failure. The project intends to evaluate this Health Navigator Program, particularly examining geographical access to the service, equity of uptake and impact on patient outcomes. Importantly, the health service utilisation of the WA population over time will be examined in order to demonstrate the population needs around the service, equitable delivery of the service and to accurately identify controls (based on demographics, ethnicity, health care utilisation history and access to services) for determining impacts on patient outcomes that can be attributed to the Health Navigator Program.			

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

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