Long term quality of life and nutritional outcomes following oesophagectomy: Ivor Lewis oesophagectomy vs minimally invasive oesophagectomy for oesophageal cancer, *A/Prof Garett Smith, Royal North Shore Hospital*

There continues a rising incidence of oesophageal cancers in Australia. Most patients present with worsening dysphagia and weight loss, however roughly a third of patients already have localised disease at time of diagnosis.

In oesophageal cancer patients, alongside traditional open surgical procedures, minimally invasive oesophagectomy has been increasingly used in recent years. The open procedures are associated with increased respiratory complications and other morbidities. Studies comparing open versus minimally invasive techniques have shown no major differences in survival or quality of oncological resection.

Despite improved oncological outcomes post-surgery, patients who survive still experience significant health-related quality of life (HRQoL) issues which may also contribute to overall poor long-term survival in patients. Studies have found short-term advantages of the minimally invasive technique, however, how these patients do in the long-term is still poorly understood and reported. Through this project, the researchers intend to assess the long-term HRQoL and nutritional outcomes in patients following open Ivor Lewis or minimally invasive oesophagectomy.

The researchers identified the cohort of patients who had an oesophagectomy at a major tertiary centre between 2001 and 2017 via review of hospital medical records and existing databases. Cohort data in the Royal North Shore Hospital oesophagectomy 2001-2017 dataset were linked by the CHeReL to mortality outcome data in the NSW RBDM Death Registrations and the Cause of Death Unit record Files (COD-URF). The researchers also plan to collect data prospectively via questionnaires, blood and stool tests.

The study findings are expected to help improve understanding of patients' quality of life and needs postoperatively and inform decision making in doctors to benefit future oesophageal cancer patients undergoing surgery. The secondary purpose of this study is to investigate the impact of oesophagectomy on patients' nutritional status and identify important nutritional deficiencies to improve patient care.

Using linked poisoning data for toxicovigilance and to improve care of poisoned patients, Dr Rose Cairns, University of Sydney

Several studies have demonstrated significant cost benefits of poisons centres, primarily in reducing unnecessary hospital presentations and admissions, and in improving care and reducing length of stay of hospitalised patients. However, there are no Australian studies that comprehensively describe poisoning epidemiology across all ages and exposure types.

The New South Wales Poisons Information Centre (NSWPIC) is Australia's largest poisons centre, taking calls from healthcare professionals and members of the public. There is limited systematic information regarding NSW poisons centre service utilisation.

The researchers of this retrospective cohort study plan to use data linked via the CHeReL to analyse patterns in poisons centre service utilisation and factors affecting utilisation to help PIC guideline development and service planning. A methodological study analysing poisoning case ascertainment in different health datasets is also planned. Geographic variation in poisonings will be studied for targeted prevention initiatives and deaths post-discharge for poisoning patients will be examined to provide guidance on the safety of driving after discharge, and guide mental health follow-up post overdose.

The cohort for this study includes NSW patients affected by poisoning, with poisoning-related records in any of the following: the NSW Poisons Information Centre (NSW PIC), Admitted Patient Data Collection (APDC), Emergency Department Data Collection (EDDC), Cause of Death Unit Record Files (COD-URF) and NSW Ambulance dataset. The CHeReL supported the study by identifying the cohort and linking cohort data from these datasets to poisoning data held by the NSW Poisons Information Centre.

Overall, the program of work is expected to provide a comprehensive overview of poisoning in NSW.

Determining the health and welfare use of New South Wales workers with long duration workers' compensation claims (the Transitions study), Prof Alex Collie, Monash University

This study aims to examine the health care and welfare (social security) use of a group of more than 4000 injured workers in New South Wales with very long periods of time off work, whose income support through the NSW workers' compensation scheme ceased in late 2017 due to changes in the state workers' compensation legislation (the Section 39 cohort).

The retrospective case-controlled cohort study will examine the extent and nature of healthcare use and welfare use in the Section 39 cohort at the conclusion of their income support and for a 12- month period after withdrawal of income support in the workers' compensation system. Health and welfare outcomes will be compared to an injured worker control group and a community control group.

The planned analysis dataset includes state and Commonwealth datasets which were linked and accessed via the CHeReL and AIHW respectively. The Section 39 cohort and injured worker comparison group were identified by the State Insurance Regulatory Authority of NSW (SIRA) and a potential community control group was identified by linkage to the Medicare Enrolment File by the AIHW. The CHeReL linked the cohort to NSW hospitalisation data from the Admitted Patient Data Collection (APDC) and the Emergency Department Data

Collection (EDDC). The AIHW linked the Department of Social Security interactions of the cohort, medical benefits and pharmaceutical benefits from the Data Over Multiple Individual Occurrences (DOMINO) dataset, the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Schedule (PBS) respectively.

The study is expected to provide new information about health and welfare outcomes of injured workers, on the impact of a major social policy change, and will for the first time examine interactions between Australian systems of income support and healthcare for injured workers.

The Antecedents of Renal Disease in Aboriginal Children and Young People (ARDAC): Understanding and moderating the trajectory towards chronic disease in young Aboriginal people, Professor Jonathan Craig, Flinders University

Addressing the gap in health between Aboriginal and non-Aboriginal Australians is a national health priority. Approximately 50% of this gap can be attributed to diseases linked by common risk factors, namely cardiovascular disease (CVD), diabetes mellitus (DM), and chronic kidney disease (CKD). As such, it is important to consider the interrelated nature of these conditions, their determinants, and their burden.

The ARDAC Study commenced in 2002 and is population-based study of 3758 participants recruited during early childhood with 57% of participants identifying as Aboriginal. The ARDAC study aims to identify early childhood factors associated with the emergence of chronic conditions over the life course. As the largest cohort study of its kind, with strong Aboriginal governance, the ARDAC Study investigates the effects of childhood hypertension, diabetes, cardiovascular, kidney health, and modifiable health risk behaviours and socio-demographic factors on overall life course outcomes between Aboriginal and non-Aboriginal participants in the ARDAC cohort.

To achieve its aims, the ARDAC study has linked its cohort data to over 20 statewide data collections via CHeReL, including the Perinatal Data Collection (PDC), Perinatal Death Reviews (PDRs), NSW APDC, NSW EDDC, Ambulance eMR/ PHCR, BDMRs, NAPLAN & ANZDATA. Commonwealth data, including the MBS and PBS data collections, was linked and provided by the Australian Institute for Health and Welfare.

With the ARDAC cohort now young adults, aged between 18 to 30 years of age, the study will address the current evidence gap for this age group for who data on chronic disease health and wellbeing are currently limited. Addressing this evidence gap is crucial because early adult life is a critical transition period for the development of chronic disease. As such, the ARDAC data linkage will generate definitive evidence on the life course trajectories for chronic conditions from childhood to early adult life among Aboriginal Australians.

Late postoperative complications after childhood hypospadias repair performed in three Children's hospitals in New South Wales between 1991 and 2006, Dr Peter Pockney, Dr Aniruddh Deshpande John Hunter Hospital

Hypospadias is the most common congenital penile anomaly. Most diagnosed children undergo surgical correction in early childhood as a single or two-stage procedure, with the aim to achieve both functional (urinary and sexual) and cosmetic normalcy.

There is currently limited knowledge on long-term outcomes of hypospadias repair, particularly the incidence and type of subsequent penile interventions. Filling this knowledge gap will help understand the risk factors of future complications requiring intervention and devise preventative strategies and improve the care of hypospadias patients of all ages.

This retrospective data linkage study included a cohort of children operated on for hypospadias in three NSW Children's hospitals between 1991 and 2005. The cohort was produced from the Medical Record Departments based on the pre-selected diagnostic and procedure codes. The CHeReL linked the cohort to the NSW APDC and EDDC to identify individuals who subsequently had penile surgery at any age between 2001 and 2020 in public or private hospitals in NSW.

The linked data will be used to analyse the incidence and type of the unplanned subsequent penile procedures and identify potential risk factors (e.g., severity of hypospadias, type of repair, presence of persistent chordee, division of the urethral plate etc.). The researchers also aim to conduct a time-to-event analysis of subsequent penile procedures. By ascertaining potential risk factors for future long-term complications and the researchers expect to be able to propose interventions to mitigate them.

Generating evidence for a strong foundation in the early years: using population health data for translational child health, healthcare and policy, Professor Natasha Nassar, University of Sydney

Long-term health, developmental and educational outcomes of many perinatal and early childhood conditions are largely unknown. These include infants born prematurely, or with other medical conditions, or born to mothers with disorders of immune or endocrine systems. Children experiencing acute or chronic health conditions or injuries throughout childhood, and undergoing subsequent procedures or interventions are also at increased risk of complications, including impacted neurodevelopment.

This data linkage project seeks to establish an Australian birth cohort of routinely collected and linked population perinatal, health, development, and education data of infants born in NSW from 1994-2015. The proposed research will utilize the cohort data to investigate the impact of early life events on subsequent child health, development, and healthcare utilization.

The specific aims of this project, for each condition or intervention, are to assess the burden of disease, assess maternal and infant characteristics and risk factors of infants with each condition, examine health outcomes, health service utilisation and associated costs for infants with and without each condition/ intervention and investigate association between presence of condition/ intervention and developmental, educational, neurodevelopmental, and mental health outcomes.

The CHeReL identified the cohort for this retrospective study consisting of infants and their mothers from NSW PDC from 1994 onwards and from all APDC separations up to age 25 years old (0-24 years at admission). The CHeReL linked cohort data to hospital and emergency admissions in the NSW APDC and EDDC respectively, death data from the RBDM and COD-URF and to the Mental Health Ambulatory Collection data. Several other datasets such as out-patients dataset, the Neonatal Intensive Care Units Study (NICUS), Register of Congenital Conditions (RoCC), NSW Mental Health Outcomes & Assessment Tools Data Collection (MH-OAT data), NSW Board of Studies NAPLAN, school attendance and HSC, Department of Family & Community Services Disability Services and Operating Room Datasets were also linked to create a comprehensive dataset.

This cohort will provide the opportunity to investigate emerging issues in child and adolescent health on a population level.

Mortality and hospitalisation outcomes of young people in primary mental health care: a 10 year follow up study, Professor Ian Hickie, University of Sydney

Understanding the risk of death from suicide in people experiencing mental distress is essential for delivering targeted clinical interventions as well as interventions at a population level. Recent analyses provide support to a disproportionate increase in emergency department presentations related to self-harm and suicidal behaviour presentations.

The data linkage study aims to establish mortality and hospitalisation outcomes over a ten-year period in a population of young people engaged in primary mental health care services. The researchers aim to establish rates of death from suicide and other causes, such as accident and injury, and where substance use or intoxication was a contributing factor, as well as rates of presentation to emergency departments and hospital admissions. The secondary aim of this study is to establish rates of presentation to emergency departments and hospital admissions.

To achieve this, mortality and hospital outcomes were linked to data already collected as part of a longitudinal study of 7000 young people (aged 12-30 years old) conducted by Brain and Mind Centre. Young people- aged between 12 and 30 years at first presentation, who attended at least one visit to the service, and consented to participate in the Brain and Mind Research Patient Register constituted the study cohort. The cohort dataset included sociodemographic, clinical, and functional data that were collected at baseline and at subsequent

visits to the health service. Baseline neuroimaging and neurocognitive assessments that were available for a subset of 1000 patients will be used to identify predictors of mortality and hospitalisation outcomes. The CHeReL facilitated the study by linking cohort data to hospital and emergency admissions in the NSW APDC and EDDC respectively, death data from the RBDM and COD-URF.

Health service utilisation and outcomes following surgery for Inflammatory Bowel Disease, Professor Jane Young, University of Sydney

Australia has one of the highest incidences of inflammatory bowel disease (IBD) in the world. While many patients with IBD can be managed with medical therapy, a few require surgery. These surgeries include those performed as an emergency operation (for example, an emergency colectomy), or those performed electively (including ileal pouch surgery).

The first part of this retrospective data linkage study looks to assess outcomes of patients undergoing IBD surgery. All individuals undergoing surgery for IBD admitted to NSW hospitals from July 2001 to March 2019 constituted the study group. Previous Australian studies in this cohort have limited to hospital based / single-centre studies. This study looks to use NSW administrative (APDC) data, linked with mortality data, to assess trends, outcomes, and health service utilisation in patients undergoing surgery for IBD, with the overall aim of identifying potential areas for improvement and ways of minimising 'unwanted' variation in outcomes following this surgery.

The second part of this study aims to validate the APDC to investigate outcomes of IBD surgery. A prospective database of all individuals undergoing ileal pouch surgery for IBD by a single surgeon and admitted to Royal Prince Alfred Hospital (RPAH), Sydney, from July 2001 to March 2019 (Ileal Pouch database) will be supplemented by comprehensive medical records review for each patient within the database and used for validation. By comparing this data to the APDC data, the accuracy of the APDC in terms of case ascertainment and diagnosis of complications can be determined. This validation study is important to guide future use of the APDC in investigating patients undergoing IBD surgery.

The CHeReL facilitated this study by identifying the cohort of all individuals in the APDC who had been diagnosed with IBD or had undergone surgery for IBD and in the Ileal Pouch database to their hospitalisation data in the APDC and death data in the NSW RBDM and COD-URF.

Macquarie MINDS: Monitoring of Injury and psychosocial health outcomes, career trajectories and continuing educatioN, LiveD experiences and Social connectedness, Dr Reidar Lystad, Macquarie University

The period from late teens to adulthood can have significant impact on the future health and well-being of individuals. The Macquarie Minds study aims to establish a large, prospective longitudinal cohort of young adults and routinely capture information on their life experiences and exposures and assess their impact on education, employment, lifestyle, health-related quality of life, well-being, social support, life events, carer responsibilities, and use of social media technology. The study findings could potentially be instrumental in understanding the determinants of healthy and resilient individuals in our society.

The pilot cohort study aims to determine the feasibility of recruiting university graduates to establish the longitudinal cohort study. The specific objectives of linking administrative health data are to determine the proportion of consented participants that can be matched to the Master Linkage Key; and to determine the proportion of such matched participants who have relevant health records in each of the data collections.

The cohort consists of Macquarie University graduates in 2018 who consented to participation in surveys and data linkage. University graduates are used as a proxy for the population of interest (i.e., emerging adults) as it allows convenient recruitment of a clearly defined cohort (i.e. graduates from a single university in a single calendar year). Primary cohort data were collected through an online registration form, baseline, and follow-up surveys and linked by the CHeReL to hospital data from NSW APDC and NSW EDDC and to NSW eMR, NSW PHCR, NSW Central Cancer Registry, NSW RBDM Death Registrations and Cause of Death Unit Record File.

The data linkage will enable the researchers to investigate individual and social factors associated with health outcomes and service use (ambulance, emergency department, hospitalisation, cancer registry, and mortality records).

Mapping the care pathway of youth and adolescents that self-harm in the Australian Capital Territory, A/Prof Alice Richardson, Australian National University

Self-harm is relatively common among young people with prevalence rates reported in adolescent samples ranging from 7.3 to 16.1%. Studies in New South Wales and Victoria found that the number of children and adolescents engaging in self harm is increasing. There is a lack of comprehensive research within Australia regarding patients who have self-harmed or have suicide ideation, who use a hospital Emergency Department (ED) as the first point of contact with the health system for mental distress.

This data linkage study is one component of The Better Care and Better Outcomes for youth experiencing self-harm study. This component of the study aims to comprehensively quantify the relationship between different paths of mental health care and repeated ED presentation using linked administrative data from Australian Capital Territory, Australia.

The primary goal of the data linkage study is to estimate the rates of re-presentation to EDs by adolescents for self-harm, and to identify the effect of treatment pathways for children and adolescents who self-harm on re-presentations to EDs. The study will use linked routinely collected data to estimate rates of readmission to emergency departments adjusting for sociodemographic characteristics such as age, sex, and severity of mental health condition.

Individuals were eligible for inclusion in the study if they were aged 12 – 25 and ever had an ED presentation or an admission to a hospital or other health facility, from 2012-2018, with a diagnosis identified by a list of ICD-10 codes related to self-harm. Cohort data was linked by the CHeReL to hospital data from ACT Admitted Patients Collection and ACT Emergency Department Data Collection DDC and death data from ACT Registry of Births, Deaths, and Marriages and Cause of Death Unit Record File, as well as mental health data from community mental health Database (MAJICeR).The study findings will help quantify the burden of ED re-presentation by individual characteristics; investigate variation in hospital-community mental health care paths by individual characteristics and to identify the optimal MH care path in relation to reducing ED representation in the ACT.

Epidemiology of congenital heart defects in Australian children and impact on health, health service utilisation, health costs, neurodevelopment and educational attainment, Dr Samantha Lain, University of Sydney

Congenital heart disease (CHD) is a structural heart abnormality and is the most common birth defect. About 3,000 affected babies are born in Australia each year. CHD is the leading cause of hospitalisation in the first decade of life, with a third of these individuals requiring surgical intervention, often open-heart surgery. Currently, ~85% of affected children survive to adulthood, however little is known about their pathways through the health system, and their health and neurodevelopmental outcomes.

This retrospective, population-based cohort study will use linked data to examine accuracy of reporting cardiac defects using hospital data, determine the prevalence of CHDs, describe and quantify CHD patient outcomes, identify factors driving poor health, neurodevelopmental, educational and mental health outcomes for children with CHD, and determine the health service usage among children with CHDs, and estimate the cost to the health system.

To facilitate this study, the CHeReL identified the cohort from the Kids Heart Biobank by linking to hospital discharge data and further linked to outcome variables concerning health (hospitalisation, procedures through linkage to the APDC, EDDC, mental health,), early child development (AEDC), Social services (Dept of Family and Community Services), school test (NAPLAN, School attendance and HSc) and survival of individuals (RBDM) with CHD will be identified from administrative datasets.

Overall, the project is expected to provide valuable insights into the health service utilisation and costs, and ongoing health, neurodevelopmental and cognitive outcomes for children with a diagnosis of CHD.

OUTBREAK: The characterisation of antimicrobial utilisation across the Illawarra Shoalhaven and Hunter New England regions, Professor Steven Djordjevic, University of Technology Sydney, Janaye Fish, Illawarra Shoalhaven Local Health

Antimicrobial resistance (AMR) is a significant public health and economic concern. AMR is associated with poor clinical outcomes, in terms of mortality and morbidity, length of hospitalisation and health care costs. Inappropriate use of antimicrobial drugs is thought to be a major risk factor for the development of AMR.

This retrospective, observational data linkage project aims to characterise and geospatially map community antimicrobial utilisation across the Illawarra Shoalhaven and Hunter New England regions of New South Wales using integrated datasets. To achieve this the researchers identified cohort of participants from the Sax Institute 45 and Up study (a longitudinal study on healthy aging of participants across New South Wales). Cohort data was linked to Pharmaceutical Benefits Scheme (PBS) and Medicare Benefits Schedule (MBS) data by the AIHW, for the researchers to characterise antimicrobial utilisation across the two pilot regions. Further, the CHeReL linked hospital data from the NSW APDC and EDDC, mortality data from the NSW RBDM and COD-URF and their history of communicable diseases from the NCIMS to enable analysis of trends and changes in community antimicrobial use and healthcare service utilisation across these two regions.

The study findings will be used to determine feasibility of subsequent linkage to private and public pathology data, and data generated from the microbiome sampling of a subset of patients within the Illawarra Shoalhaven region.

Data on antimicrobial use and healthcare service utilisation is essential in understanding the factors that influence prescribing practices, and in monitoring the efficacy of interventions designed to improve antibiotic stewardship.

Assessing unmet needs in palliative care in Illawarra Shoalhaven, Prof Kathy Eagar, University of Wollongong

With an ageing population and growing burden of chronic disease, end-of-life care is an increasingly important issue. Palliative care is known to improve patient and family outcomes, and there is emerging evidence to suggest that it is also cost-effective. Accurate information about the demand and supply for palliative care and delivery of non-beneficial or poor-quality care at end of life is required at a regional level to enable population-based planning. The proposed project aims to address the gap in knowledge of local patterns of morbidity and death and quality of end-of-life care in the Illawarra Shoalhaven region. Using

health data, proposed project will assess the level of potential unmet need for palliative care at the end of life and the level of potential non-beneficial care at end of life among the residents.

This is population-based retrospective observational study of residents in the Illawarra Shoalhaven (Local Government Areas of Illawarra) aged 15 years and over who died from 2013-2017. Analysis will be inclusive of data in the 2 years prior to death.

The clinical and service information required for this analysis were sourced and linked by the researchers from the Illawarra Shoalhaven LHD datasets. Further, the CHeReL provided mortality data i.e. death registration and cause of death data by linking to RBDM and ACR COD_URF.

By identifying any specific gaps or indications of suboptimal care by patient subgroups, the results will be readily translatable into strategic service planning, policy and practice.

COSMIC: Colorectal cancer Outcomes in people with Severe Mental illness, Professor Steve Kisely, University of Queensland

Cancer is one of the major causes of death among people with a psychiatric illness. Our previous research has shown that cancer incidence rates in people with severe mental illness (SMI) - i.e., those with schizophrenia or bipolar affective disorder, are similar to those in the general population, but that cancer mortality is higher in those with SMI than those in the general population. Possible reasons include poor cancer screening participation rates in those with mental illness, delays in diagnosis leading to more advanced disease at diagnosis, and sub-optimal post-diagnosis management.

The researchers of this project utilised data from the Australia's National Bowel Cancer Screening Program (NBCSP) to determine where the major barriers to optimal cancer care for those with SMI occur. The researchers will test the hypothesis that people with SMI have lower screening rates and are more likely to present with more advanced cancer. They are also less likely to receive the appropriate specialist surgical procedures, chemotherapy or radiotherapy.

People with SMI were identified from the prescribing data in Pharmaceutical Benefits Scheme (PBS) for second generation antipsychotics, indicated solely for treatment of either schizophrenia or bipolar affective disorder or lithium prescriptions, indicated for bipolar affective disorder.

This data linkage study aims to use Commonwealth data (NBCSP, Medicare Enrolment File, Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, Australian Cancer Database and the National Death Index) to compare bowel cancer screening participation in people with SMI to those from the general population.

Additionally, the researchers accessed linked NSW Cancer Registry and hospital data via the CHeReL to examine care pathways from diagnosis through treatment and end-of-life care.

A dashboard of predictive analytics and decision support to drive care quality and person-centred outcomes in aged care, Professor Johanna Westbrook, Macquarie University

Dashboards are a vehicle for data integration, predictive analytics, and decision support. Clinical dashboards provide visual representations of patient status and clinical environments that change dynamically in real-time.

The aim of this project is to develop a digital dashboard of integrated information, risk indicators and decision support, to better identify and support older adults at risk of poor outcomes in residential and community-based aged care with special focus on two priority aged-care challenges, namely falls and client wellbeing.

The CHeReL facilitated this project by linking , routinely collected retrospective health and aged care data from the NSW APDC, NSW EDDC and death data from the NSW RBDM to retrospective, non-identifiable data from the care management system of a large aged-care provider. Linked data will be used to develop and validate risk models that can identify aged care clients at risk of poor outcomes (i.e., fall-related hospitalisations and low wellbeing scores). The resulting aggregate risk models will be used in the dashboard to identify and improve the care of at-risk clients. Linked data via the CHeReL will also be used to evaluate the impact of a stepped-wedge cluster randomised controlled trial of the dashboard on the care and outcomes of aged care clients.

The dashboard is expected to help aged care managers monitor the quality of the care they provide; support general practitioners and care staff to obtain an overview of each client at a glance; and deliver information to aged care clients and their families.

Surgery for non-malignant polyps in the era of advanced endoscopic therapeutic techniques: A state-wide retrospective analysis, Professor Michael Bourke, Westmead Clinical School / Westmead Hospital

Australia has one of the highest rates of colorectal cancer (CRC) in the world. Early detection and definitive treatment have shown to reduce colorectal cancer morbidity and mortality. Screening programs have resulted in the identification of large pre-malignant lesions in asymptomatic individuals. Development of advanced polypectomy techniques has meant most of the non-malignant polyps can now be managed safely and cost-effectively through endoscopic removal. There is no published Australian data on the prevalence of traditional surgery for non-malignant polyps or local post-operative mortality and morbidity data for this indication.

This retrospective cross-sectional study aims to estimate the rates of surgery for non-malignant polyps compared to rates of surgery for malignant lesions. The study cohort of all patients in NSW who underwent colorectal surgery for non-malignant polyps between mid-2007 – 2017 were identified from the Admitted Patients Dataset Collection by the CHeReL using procedure and diagnosis ICD codes. Further, the CHeReL linked cohort data to the NSW Cancer Registry, the NSW EDDC and death data from NSW RBDM. Using linked data, the researchers aim to explore all aspects of cost and highlight key areas of cost saving and the potential to reduce strains on surgical wait lists and reduce poor outcomes for patients.

Using additional diagnoses recorded in the APDC the investigators aim to capture adverse events and determine risk factors for morbidity and mortality. Cost of admission and length of stay for admissions that contained adverse events compared to uneventful admissions will also be estimated.

Overall, the study findings will allow clinicians to better inform their patients on management options for complex polyps, highlight a key area of cost saving and will provide data to justify better referral pathways to expert endoscopists for management of these lesions.

Parenting and intergenerational disadvantage: A population trial of the Triple P system of parenting and family support, Professor Matthew Sanders. The University of Queensland

This research project is a large-scale study of the impact of enhanced parenting support on indicators of wellbeing, risk and disadvantage at a community level. The study aims to compare thirty-two Queensland communities (Intervention) with matched NSW comparison communities (Comparison) on a number of outcomes. Intervention involves a three-year implementation of the Triple P - Positive Parenting System. Triple P incorporates five levels of intervention on a tiered continuum of increasing strength and narrowing population reach for parents of children from birth to age 16. Outcomes include child maltreatment, non-accidental injuries and emergency department visits, school attendance and achievement, family breakdown and community connectedness.

The research questions to be addressed will focus on child physical and mental health, and parent mental health. The study cohort included all babies in the Perinatal Data Collection born since 2005, their mothers and their other parents identified in the Registry of Births, Deaths and Marriages birth registrations. Population health information sourced from ongoing data collections via the CHeReL includes hospitalisation data from the NSW APDC and EDDC, birth and death data from the NSW RBDM, Perinatal Data Collection, Cancer Registry data and the Mental Health Ambulatory Data Collection.

The researchers will use cohort linked health data, multiple government administrative data-assets and a two time-point prospective survey data for their research and evaluation. Data will be used to understand and quantify aspects of physical and mental health of parents and children living in the intervention and

comparison sites as part of the evaluation process. Linked data that focuses on the health and wellbeing of entire populations of children and parents will provide researchers with a comprehensive picture of health and wellbeing at the population level and enable them to monitor trends over time.

Variations in Care for Pancreaticoduodenectomy in NSW - An outcome and cost analyses, Professor Vincent Lam, Macquarie University

Pancreatic cancer is the fifth most common cause of cancer death in NSW. Pancreaticoduodenectomy provides the only chance of cure for cancers in the head of the pancreas. Pancreaticoduodenectomy is a high acuity procedure associated with significant morbidity, mortality, and financial costs. It has previously been shown that there is significant variation in patient outcomes following pancreaticoduodenectomies in NSW including large differences in cost, perioperative mortality, readmissions, and hospital stay.

This retrospective cohort study using linked data aims to examine the variation in costs for patients who underwent pancreaticoduodenectomies in NSW public hospitals, evaluate any hospital and patient specific variables contributing to the cost, and examine the association between cost and postoperative patient outcomes. The study will also use linked data to explore if high volume centres have lower patient mortality rates, lower readmission rates as well as cheaper in-hospital cost when compared to low volume centres. The CHeReL supported this study by extracting and linking de-identified cohort data from the NSW Central Cancer Registry, hospital data from Admitted Patients Dataset Collection, death data from NSW Registry of Births, Deaths and Marriages and the Cause of Death Unit Record File, healthcare cost data from Activity Based Management department of NSW Ministry of Health, and the NSW National Weighted Activity Unit (NWAU)

The resultant data analyses may strengthen the argument for the current centralisation of pancreaticoduodenectomy in NSW and help in further defining a best practice model for NSW.

The impact of specialist neonatal carer on long term child outcomes, Dr Serena Yu, University of Technology Sydney

There is a paucity of evidence in relation to the long-term outcomes of neonatal care - an area of intensive resource use and rapid medical advances. Significant data limitations and the infeasibility of randomising the care of very sick babies for a clinical trial, are barriers to understanding neonatal care costs and long terms gains.

This project aims to use well-established quasi-experimental methods to approximate the results of a randomised trial, and utilise population-based administrative data, including sociodemographic data, to compare the care,

health outcomes and costs of different cohorts of newborn babies, and particularly at-risk babies – for the first five years of life.

Singleton babies born in NSW from 2004 - 2018, and NSW women who had a singleton pregnancy over the same period were included in this study. The CHeReL identified the cohort from the Perinatal data Collection and linked cohort data to NSW Admitted Patient Data Collection (APDC), NSW Emergency Department Data Collection (EDDC), Neonatal Intensive Care Units Data Collection (NICUS), Registry of Births, Deaths and Marriages (death and birth registration data), and the Australian Early Development Census. In addition, data from the Commonwealth Department of Human Services (Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data) were linked to identify long-term healthcare cost and service use.

The research findings will address a significant evidence gap pertaining to the long-term outcomes following specialist neonatal care, and how this interacts with the social determinants of health. The outcomes of this project will be to inform decision-making by policymakers, administrators, clinicians and consumers, redress inequalities where they exist, and improve resource use.

NSW Benign Colorectal Diseases Study, Professor Vincent Lam, Macquarie University

Benign colorectal diseases such as diverticulitis, benign perianal disease and inflammatory bowel disease (IBD) account for a significant burden of disease to Australia's hospital system. Despite the frequency of these diseases, there is limited up-to-date data on the epidemiology, disease burden and health care cost in Australia.

This retrospective cohort study explores the epidemiology of a range of both common and less common benign colorectal diseases. This project aims to utilise pre-existing databases collected by NSW and linked by the CHeReL to investigate the in-hospital management and outcomes of a range of benign colorectal diseases from 2005 onwards. All adults presenting to NSW hospitals from both APDC and EDDC databases with separation time from 2005 onwards with benign colorectal diseases will be included. The CHeReL identified the cohort and linked cohort data to NSW Admitted Patient Data Collection (APDC), Emergency Department Data Collection (EDDC), Cause of Death Unit Record File (COD-URF), Cancer Registry (CR) and Registry of Births, Deaths and Marriages (RBDM).

Linked longitudinal data will enable the researchers to study long term trends and outcomes of patients with benign colorectal diseases and help in identifying successful management strategies especially in areas of controversy eg. management of acute diverticulitis, pilonidal sinus, haemorrhoids. In addition, it is hoped the long-term data may confirm or refute disease associations such as between diverticulitis and bowel cancer. The study findings will provide an insight in disease epidemiology, disease progression, patient outcomes,

management strategies and complications for a range of benign colorectal diseases in NSW hospitals.

The economic impact of providing precision medicine through whole genome sequencing – Mitochondrial disease cohort, Professor Deborah Schofield, Macquarie University

Clinical manifestations of mitochondrial disorders in adults include muscle weakness, fatigue, cardiomyopathy, stroke-like episodes, deafness, diabetes, and eye problems. There is currently no reliable diagnostic approach available. Recent advances in genomic diagnostic indicator testing and metabolomic tests shows potential for greater than 90% diagnostic sensitivity.

The aims of this cross-sectional observational study including a cohort of individuals with mitochondrial disease is to evaluate hospital resources used by mitochondrial disorder patients, assess comorbidities experienced by individuals affected by patients with mitochondrial disorders, and to evaluate the economic impact of genetic sequencing in mitochondrial disorders.

The EPIC-Mito study will recruit 250 individuals with mitochondrial disease and collect cross-sectional data through a survey questionnaire. The study will use Medicare and pharmaceutical claims data from Services Australia, and hospital admissions, emergency departments and outpatient records datasets held by NSW Ministry of Health linked to Survey data via the CHeReL. A microsimulation model will be developed from the data collected. The research will determine health burden due to mitochondrial diseases and the extent to which clinical genomics can reduce these impacts.

Falls risk associated with cataract and after first and second eye cataract surgery, Associate Professor Soufiane Boufous, The University of New South Wales

Falls incur over $1 billion in treatment, disability, lost output and mortality each year in Australia. People with cataract are at approximately 3-times increased risk, making fall prevention a critical public health issue.

The aims of the prospective, 24-month cohort study are to measure temporal changes in the rate of falls and falls requiring medical attention, before cataract surgery of first eye, between first and second eye and after second eye surgery. A second aim is to characterise the visual function in older people in these time-periods and investigate vision-related mechanisms for increases in falls risk, adjusting for known predictors of falls. This study also aims to evaluate healthcare costs for each participant in each time period and compare the costs for those who fell and those who did not during the study period.

The cohort for this study includes patients aged 65 years or older with bilateral cataract presenting for surgery at public hospital eye clinics in Sydney, Melbourne, Perth and Adelaide. The investigators plan to use linked data to

identify and capture falls requiring medical care, and cross-check against self-reported falls. These will be obtained by linking study cohort data to hospital and emergency datasets in each state as well as the Medicare Benefits Schedule (MBS). For NSW, the CHEREL linked the Cataract Surgery Cohort Study data to the Admitted Patients Dataset Collection, Emergency Department Data Collection and death data from Registry of Births, Deaths and Marriages and Australian Coordinating Registry Cause of Death Unit Record Files.

With limited resources to shorten public waiting lists, there is a need to understand an individuals' risk of fall injury or other negative consequences while waiting for surgery. This important project will inform the development of strategies to reduce falls risk in the many older people with cataract.

Assessing risk and predicting harms of prescribed opioids, Professor Louisa Degenhardt, The University of New South Wales

Australian opioid prescribing increased fifteen-fold in the last two decades. Originally registered to manage cancer and acute pain, opioids are now approved to treat an increasing number of conditions, especially chronic noncancer pain which has traditionally been undertreated. However, in parallel to escalating use, there is also evidence of increasing opioid related hospitalisation, dependence and overdose, indicating that at least some of the growth in prescribing is not consistent with quality medicine use.

The aims of this study are to examine the magnitude of risk for adverse outcomes across different opioids and formulations for a range of known (e.g. overdose, dependence) and potential opioid risks (e.g. falls resulting in emergency department visits and hospitalisation), towards a comprehensive documentation of risks for all prescribed opioids in Australia. The study will also identify risk factors for those adverse outcomes, including clinical, prescriber and treatment-related characteristics, among different patient groups (such as cancer, CNCP and acute pain); and use machine learning methods to develop risk prediction models to identify those who are at highest risk of adverse outcomes

This retrospective observational data linkage study includes eight Commonwealth and NSW collections. The study cohort includes NSW residents who started a new opioid dispensing episode from 2002, derived from the Pharmaceutical Benefits Scheme (PBS) dataset held by the AIHW and then linked in-house to Medical Benefits Scheme, Australian Cancer Database, National Death Index. The CHeReL provided linked records from the NSW-based datasets (Admitted Patient Data Collection, Emergency Department Data Collection, Mental Health Ambulatory Data Collection and the Pharmaceutical Drugs of Addiction) and the ACT-based datasets (Admitted Patient Collection and Emergency Department Data Collection) to AIHW for linkage to the cohort.

The study is expected to provide valuable information about the drivers of long-term prescribed opioid use, nonadherence, dependence, overdose and other harms.

Prescribing medicine use and healthcare contacts before suicide: Detecting opportunities for intervention and prevention using population-based linkage of routinely collected data, Dr Kate Chitty, University of Sydney

In Australia, suicide is the leading cause of death for people aged 15–44 years. Health professionals deliver most of our key suicide prevention strategies via health services, but other efficacious population-level strategies include means restriction and public awareness campaigns. Currently, we have no population-level data allowing us to determine which individuals, in what parts of Australia, are likely to use our most promising interventions delivered by health services. The aims of this study are to describe: (1) health service utilisation rates in the year prior to death by suicide, and how this varies by individual case characteristics; (2) prescribed medicines use in the year prior to death by suicide, medicines used in suicide by poisoning and how this varies by individual case characteristics. The cohort for this population-based case series study included all intentional deaths that occurred in Australia between 2013 and 2019 as derived from the National Coronial Information System (NCIS). Cohort data were linked to routinely collected data from the Pharmaceutical Benefits Scheme (PBS), and the Medicare Benefits Scheme (MBS) by the AIHW and to NSW Health state-based information from the following collections: Admitted Patient Data Collection, Mental Health Ambulatory Data and Emergency Department Data Collection. Linking routinely collected data on prescribed psychotropic medicines and mental healthcare prior to suicide death offers an opportunity to comprehensively examine the use of these treatments before suicide.

Description and prediction outcome of drowning patients in New South Wales,Associate Professor Michael Dinh, NSW Agency for Clinical Innovation

Drowning is a preventable cause of death, with a high significance in young people. Drowning is one of the top five leading causes of death amongst those ages 1-14 years in Australia with the largest number of drowning deaths in Australia being from New South Wales. Patients who experience drowning, can have different outcome ranging from full recovery to death.

This study aims to explore the outcome of patients who are admitted to hospitals for drowning in the NSW and investigate prediction of patients' outcome based on accessible data.

The cohort for this retrospective study was defined from drowning cases identified in the NSW Ambulance dataset (NSW Amb) and using select ICD codes in the NSW Admitted Patient Data Collection. The CHeReL then linked cohort data to all matching records from the APDC, NSW Amb, Emergency Department Data Collection and to death data from NSW Registry of Births, Deaths and Marriages and Cause of Death Unit Record File.

The study will provide outcome data for drowning patients which would contribute in producing better models of care for drowning patients across NSW. Ultimately, the results of the study will provide data to enable efficient and effective hospital care for drowning patients. The current pathways of care and guidelines could be updated based on the results of the study.

Impact of chronic health conditions and injury on school performance and health outcomes of children: pilot study, Associate Professor Rebecca Mitchell, Macquarie University

Different types of injuries can affect children in different ways and serious injuries can adversely impact on the child's psychological and physical health, school performance, and their long-term quality of life. Chronic health conditions can also have an adverse impact on a child and their ability to perform well at school and to complete their schooling.

The overall objective of this longitudinal, population-based case-comparison study of injured or chronically ill children is to examine school completion, education performance and health outcomes of children who were hospitalised with an injury or a chronic health condition. Cases were identified by a principal diagnosis of injury or a principal or any diagnosis or some common chronic conditions while the comparison group consisted of children ≤ 18 years of age (identified through the NSW Registry of births) who did not have any of the diagnosis codes assigned to the cases.

Cases and comparator group were identified through data extraction by the CHeReL from NSW hospitalisation data (Admitted Patient Data Collection (APDC), Emergency Department Data Collection (EDDC)) and the NSW Registry of Births. The study cohort was linked to matching records from the APDC, EDDC , Mental Health ambulatory client contacts - to capture health service use and health outcomes; to mortality data from NSW Registry of Births, Deaths and Marriages and the Cause of Death Unit Record File; and to the National Assessment Plan for Literacy and Numeracy (NAPLAN) dataset, NSW school enrolment form information, high school completions- to capture scholastic performance and school enrolment.

The study findings will provide valuable information on factors influencing school performance of injured or chronically ill children compared to their matched peers, identify factors that either positively or negatively mediate young people completing high school and assess characteristics of long-term health service utilization and hospital treatment cost among injured or chronically ill children.

Variation in mortality of hepatocellular carcinoma in NSW: a population-based data linkage study,Associate Professor Amany Zekry, The University of New South Wales

The incidence of liver cancer in Australia is increasing. Survival rates in Australia, as in other nations are poor. Hepatocellular carcinoma (HCC) is the most common type of primary liver cancer, representing 75-90% of liver cancers. Clear geographic differences in HCC incidence and mortality are seen throughout Australia. These variations may be due to differences in access to screening and preventative healthcare, as well as differences in the prevalence of risk factors between populations

This study aims to determine if there is geographic variation in HCC associated mortality across NSW and to identify factors associated with greater mortality. The role of patient location in terms of the prevalence of viral hepatitis and diabetes, social disadvantage and access to HCC care will be investigated. The study outcomes include estimation of overall and disease-specific survival after HCC diagnosis, patient and system characteristics associated with earlier mortality, geographical mapping of the prevalence of HCC and its aetiologies and variation in survival after HCC diagnosis.

The study cohort included persons diagnosed with HCC in NSW between July 2001 and December 2015 identified through the NSW Central Cancer Registry and NSW Admitted Patient Data Collection. Cohort data from these two datasets were linked by the CHeREL to mortality data from the NSW Registry of Births Deaths and Marriages and Australian Coordinating Registry Cause of Death Unit Record File and to NSW Notifiable Conditions Information Management System to capture history of infections. Aggregated non-identifying data on cases of diabetes by area within NSW from the National Diabetes Services Scheme (NDSS) registry and publicly available data on socioeconomic Index for Areas (SEIFA), national reports for the Hepatitis B and Hepatitis C Mapping Project will also be utilised for the analysis.

Findings from this study could potentially inform strategic planning of prevention programs, as well as research and health system resource allocation.

The economic and social impacts of genetic sequencing for intellectual disability (EPIC-ID, Professor Deborah Schofield, Macquarie University

Severe intellectual disability (ID) is an important unmet diagnostic and management challenge due to its high prevalence, life-long nature, and rate of recurrence within families. Despite its significant impact, there is relatively little data on the cost of ID in Australia, and thus the capacity to quantify the benefits of effectively treating or preventing ID is limited. Next Generation Sequencing (NGS) has increased knowledge of ID aetiology. Current evidence suggests that whole genome sequencing (WGS) will provide the capacity to quickly diagnose the cause of about 60% of severe ID, shortening the time to diagnosis.

This study will analyse the health services (including hospital admissions and emergency department presentations) used by patients with ID and assess comorbidities experienced by individuals affected by intellectual disability. The

investigators will then determine the extent to which clinical genomics can contribute to ameliorating these impacts.

This data linkage study includes a retrospective and a prospective cohort of individuals who are the primary carers of a child or relative with ID. The child or relative(s) with ID in the prospective group will be offered genomic testing. Information will be collected from both groups using the baseline questionnaire and from two follow-up questionnaires at one month and 12 months after receiving the results of genomic testing from the prospective group only. Cohort data (EPIC-ID dataset) will be linked to NSW Admitted Patient Data Collection and Emergency Department Data Collection by the CHeReL and to Medicare Benefits Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS) by the AIHW. Survey and linked data will used to quantify the economic and psychosocial impacts of caring for children or relatives with ID and economic costs of ID to the Australian government including the health system and other government departments such as education and social security.

Quality in General Practice - trial of a funding model in primary care, Professor Andrew Bonney, University of Wollongong

This cluster randomised controlled trial aims to evaluate the impact of an outcomes-based funding model in primary care practice. The model provides targeted practice incentives for patient enrolment with a preferred provider, longer consultations, same day access and structured follow-up after hospitalisation. The impact of the model on quality of care and health service utilisation for patients at increased risk of hospitalisation will be compared to usual care.

The primary data for this study (EQuIP data set) includes Survey data collected from staff and patients enrolled in the trial at 33 general practices across NSW (11 practices), Victoria (12 practices) and Tasmania (10 practices). The primary survey data will be linked to Admitted Patient Data Collection, Emergency Department Data Collection and to death registrations from the Registry of Births, Deaths and Marriages from NSW, Victoria and Tasmania by the respective state linkage agency and to Pharmaceutical Benefits Schedule (PBS) and Medicare Benefits Schedule (MBS) by the Commonwealth Department of Human Services. Additionally, the evaluation study will also use six-monthly data extracted from electronic patient records via Medicine Insight program and quarterly data extracted from electronic patient records by practice staff.

The study will primarily test the hypothesis that among high-risk patients and children attending general practices, the introduction of a practice-level service model incorporating continuous and graded quality improvement incentives, will improve patient-perceived relational continuity. Secondary outcome measures include rates of prescriptions, pathology, imaging, hospitalisation and downstream health system costs.

GuideLine-concordANt breast Cancer surgEry and Radiotherapy (the GLANCER study), Dr Marina van Leeuwen, The University of New South Wales

The Optimal Care Pathway for Women with Breast Cancer together with The Cancer Australia Statement – Influencing Best Practice in Breast Cancer sets out guidelines for best practice in breast cancer care.

The aim of this retrospective cross-jurisdictional record linkage study is to use linked data to investigate unwarranted clinical variation in relation to current best-practice surgical and radiotherapy guidelines that were identified through preliminary studies. Specifically, the following aspects of guideline-concordant care will be examined: breast conserving surgery in women with early-stage breast cancer; hypofractionated radiotherapy in women with early-stage breast cancer; reoperation following breast conserving surgery; breast reconstruction following mastectomy; and sentinel lymph node biopsy in patients with preoperative ductal carcinoma insitu (DCIS).

The CHeREL facilitated this study by identifying a cohort of adult breast cancer cases on the NSW Central Cancer Registry (CCR) and/or the NSW Admitted Patient Data Collection (APDC) between July 2001 and December 2018 and by linking cohort data with data from BreastScreen NSW and the NSW Clinical Cancer Registry (ClinCR). The cohort data have also been linked with the National Death Index (NDI), the Medicare Benefits Schedule (MBS), and the Pharmaceutical Benefits Scheme (PBS) by Australian Institute of Health and Welfare (AIHW).

By identifying factors amenable to changes in policy and practice, this project has the potential to directly impact the delivery of breast cancer care in Australia.

Measuring medication adherence: application of group-based trajectory model for Australians with chronic health conditions requiring continuous use of medication, Mr. Kyu Hyung Park, Macquarie University

Poor medication adherence (MA) for chronic conditions is known to increase morbidity, mortality and healthcare spending. Traditional measures of medication adherence estimate the amount of medicine taken relative to the total amount prescribed and do not consider longitudinal patterns of taking medications. The recently developed group-based trajectory model (GBTM) considers longitudinal patterns of medication consumption, allowing researchers to differentiate between alternative patterns or ‘types’ of non-adherence and to measure their effect on health outcomes. This allows clinicians to tailor interventions to the particular characteristics and medication needs of patient groups based on their pattern of medication consumption.

The data linkage study aims to explore the use of GBTM to define medication adherence for Australians with three chronic health conditions – depression, cardiovascular disease and osteoporosis.

45 and Up Study participants who used medications within the specified ATC medication codes constituted the study cohort. The CHeReL linked cohort data (linked to Medicare Benefits Schedule and Pharmaceutical Benefits Schedule) to matching records from NSW Admitted Patient Data Collection, Emergency Department Data Collection, Australian Coordinating Registry Cause of Death Unit Record Files and the Mental Health Ambulant Data collection.

Linked data will be used to identify adherence types based on patterns of medication consumption; finding relationships between adherence type and patient characteristics, health outcomes and healthcare resource use; and evaluating the potential benefits of using the GBTM in measuring medication adherence, compared to the traditional measures.

The research findings are expected to inform the development of targeted public health interventions to help improve adherence, thereby leading to better health outcomes and more efficient healthcare.

Indigenous Medication Review Service (IMeRSe) – a feasibility study, Professor Amanda Wheeler, Griffith University

The Indigenous Medication Review Service (IMeRSe) is a Commonwealth funded feasibility study as part of the Pharmacy Trial Program, across 9 sites (in Queensland, Northern territory and New South Wales) in Australia. It involves the development and evaluation of a culturally responsive medication review service, to be undertaken by community pharmacists on a fee-for-service basis in conjunction with Aboriginal Health Services.

Linked data will be used in the pre-post observational study to investigate the feasibility of identifying 'serious medication-related problems' through the use of a pre-specified list of potentially preventable medication-related hospitalisations (PPMRHs), and to see if this list can be used to estimate the effect of the IMeRSe intervention on hospitalisation rates, and to investigate study enrolment rates and retention rates to inform a future RCT.

For NSW, the study cohort was defined as any participant in IMeRSe who was recruited in one of four NSW sites (including Gunnedah, Brewarrina, Nowra and Moree) and has provided consent to release hospital admission data. The CHeReL linked cohort data to hospital admissions (NSW Admitted Patient Data Collection, Emergency Department Data Collection) for one year prior to and six months after enrolment in IMeRSe. Similar linkages of hospitalisation data to the locally recruited cohorts will be carried out in Queensland and Northern Territory. Linked data from the Medicare Benefits Schedule and Pharmaceutical Benefits Schedule will be provided by the Commonwealth Department of Health.

The project will be carried out in partnership between Griffith University, the National Aboriginal Community Controlled Health Organisation (NACCHO) and the Pharmacy Guild of Australia and is expected to support Indigenous peoples, especially those with long-term conditions, to manage their medicines safely and improve their health and wellbeing.

Tracking patients who have been discharged from a community palliative care service, Dr Davinia Seah, University of Technology Sydney

The demand for palliative care services are projected to increase as the population ages and the population grows. As the number of deaths are expected to double by 2040 in Australia, having efficient use of a specialist community palliative care team becomes increasingly important to support people who want to remain at home. While most patients are discharged because of death, some patients are discharged from community palliative care service because they have stabilised and no longer require specialist palliative care. The aim of this project is to track the outcomes and health service utilisation of these patients.

Specifically, the researchers will use linked data to track ambulance call outs, emergency department (ED) presentations, hospital admissions and the length of stay of each admission, intensive care unit admissions and the length of stay of each admission, place of death after discharge.

The cohort for this retrospective cohort study included all patients who were discharged alive from the Sacred Heart Health Service community palliative care service between July 2010- July 2016 and were followed up until death or censored at the end of 2018. Cohort data was extracted from the Sacred Heart Palliative Care System database and linked by the CHeReL to hospitalisation data from NSW Admitted Patient Data Collection and Emergency Department Data Collection, Death data from the Registry of Births , Deaths and Marriages and Australian Coordinating Registry Cause of Death Unit Record Files and to NSW Ambulance dataset.

The study findings will be used to improve discharging practices and resource planning for community palliative care services. Further, the results will be presented and disseminated at relevant department meetings and conferences to influence decision making at a local hospital level, but also statewide level.

Evaluating Healthy Ageing in Australia (New South Wales state-based datasets), Professor Steve Wesselingh, South Australian Health and Medical Research Institute

Australia is a country with an ageing population. Currently 7% of those aged 65+ are receiving residential aged care services, and they account for 40-50% of hospitalisations and days spent in hospital and also have high rates of ambulance service utilisation. There is an urgent need to better coordinate and

integrate information about people receiving aged care services, so that decision-making and practices achieve quality, coordinated, efficient, innovative and age-friendly services and outcomes.

The primary aim of this population based observational cohort study is to describe the epidemiology of aged care recipients and their service utilisation (i.e. aged care and health care) from 2002 to 2017. The secondary aims of the study include an evaluation of the risk factors for death and other health-related events in this population, and to identify successful areas and areas for improvement.

The cohort for the national study is defined as older Australians (aged 65+ years or, 50+ years and of Aboriginal or Torres Strait Islander descent) who have been assessed for and/or received aged care services between 2002 and 2017, including those who received residential aged care, home care package programmes, transition care packages, and home and community care support during the study period. The National cohort includes records in the National Aged Care Data Clearinghouse (NACDC), linked to the National Death Index (NDI), Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), and to state-based hospitalisation datasets for residents from each participating jurisdiction. For the NSW subset of the national cohort, The CHeReL provided linked records from the Emergency Department Data Collection, Admitted Patient Data Collection and Ambulance datasets to the AIHW for linkage for the Registry of Senior Australians (ROSA) research team.

The study findings are expected to guide evidence-driven decision-making across public and private aged care sectors in Australia.

Use of big data to investigate factors that promote, constrain or prevent the emergence of social and spatial inequities in health, behaviours and health services use across middle to older age, Professor Thomas Astell Burt, University of Wollongong

Built and natural environment are now recognised as modifiable levers for improving the prevention and management of noncommunicable diseases through pathways such as physical activity and sedentary behaviour, diet, sleep, social relationships, and stress. Places where people live not only contribute to their health but are also likely to influence their use of healthcare and related economic costs and playing a role in whether people end up in hospital for potentially preventable reasons.

This project aims to examine change and stability in built and natural environment in Sydney and other urban areas and how these exposures affect trajectories and inequities in health outcomes, health-related behaviours, health service use and economic costs. The aim is to understand the effectiveness and cost-effectiveness of potential environmental interventions that may keep people healthy and out of hospital.

This study will use data from participants in Wave 1 and Wave 2 of the Sax Institute's 45 and Up Study, as well as data from those who took part in Social Economic and Environmental Factors (SEEF) sub-study. This multilevel longitudinal study will utilise bespoke environmental indicators and routinely collected hospital, emergency department and mortality records linked to approximately 110,000 Wave 1 participants who lived in the major cities within NSW of Sydney, Wollongong and Newcastle.

The CHeREL facilitated this study by linking cohort data to records from the NSW Admitted Patient Data Collection, Emergency Department Data Collection, RBDM Death Registrations and the Australian Coordinating Registry Cause of Death Unit Record File

The planned overall outcome is to make high quality evidence available to decision-makers at all levels of government and city planning to bolster the business case for investing in healthier urban environments.

Perioperative Risk Assessment and Modification in Patients on Renal Replacement Therapy NSW/ACT, Dr Magid Fahim, Princess Alexandra Hospital, University of Queensland

Patients who suffer kidney failure need Renal Replacement Therapy (RRT) such as dialysis or a renal transplant to survive. Patients on (RRT) are hospitalised frequently including for surgical procedures to either save their life or improve their quality of life. However, patients with kidney failure are often considered 'high risk' for surgery due to their ill health. The aim of this project is to define the type and frequency of surgical intervention in Australasian dialysis and transplant patients, and also identify their outcomes and outcome determinants in order to facilitate doctor-patient discussions and ensuring that a well-informed decision is made when considering surgery.

The proposed research involves linkage of national surgical hospitalisation and outcome data from Admitted Patient Data Collection (ADPC) units (all states and territories and New Zealand) with the Australasian renal replacement therapy registry (ANZDATA) to develop a comprehensive and robust perioperative dataset of patients receiving renal replacement therapy who have undergone surgical intervention.

The NSW and ACT cohort of patients for this research included adult incident and prevalent RRT patients registered ANZDATA Registry from 1 July 2001 (for NSW) and I July 2004 (for ACT) who had a record in NSW/ACT Admitted Patient Dataset with a diagnosis or procedure code related to surgery from a predetermined list of codes. The CHeReL facilitated the study by linking the ANZDATA Registry data to the NSW APDC and ACT Admitted Patient Care dataset (APC).

This study is expected to describe the surgical disease burden in patients on RRT and answer important questions around perioperative RRT outcomes by providing novel epidemiological, outcome and risk prediction data.

An evaluation study of the New South Wales Involuntary Drug and Alcohol Treatment (IDAT) Program, Professor Alison Ritter, The University of New South Wales

The NSW Involuntary Drug and Alcohol Treatment (IDAT) program started in NSW in May 2012 to provide involuntary treatment as the last resort option to people who are severely dependent on alcohol and/or drugs who may be at risk of serious harm and for whom no other treatments have worked. This data linkage study is part of part of a broader follow-up evaluation program that aims to examine the effectiveness of the IDAT program. A process evaluation, cost assessment, and an outcome evaluation were also carried out under the evaluation program.

The data linkage sub-study is focused on health service utilisation (HSU) and aims to measure the change in HSU outcomes for IDAT patients (12-month pre and 12-month post treatment), and to compare HSU outcomes between the IDAT patients and a control group.

The study cohort included all IDAT patients who received treatment at the IDAT program since the program's commencement in May 2012 and the control group consisted of persons with alcohol or meth/amphetamine dependence, who were frequent attenders at hospitals and had received some form of treatment at least once, but not received IDAT. Both groups were identified by the CHeReL through data linkage and linked to routinely collected administrative data from five data collections: NSW Admitted Patient Data Collection (APDC), NSW Emergency Department Data Collection (EDDC), NSW Drug and Alcohol Minimum Data Set (NSW MDS DATS), NSW Mental Health Ambulatory Data Collection (MHADC) and NSW Mortality Data (RBDM).

This study will provide evidence to assist the NSW Ministry of Health and the Local Health Districts in their decision-making regarding the future of the IDAT program.

Physical and mental health, costs and health service use associated with obesity and bariatric surgery, Professor Alison Venn, University of Tasmania

There is considerable evidence from clinical trials supporting the effectiveness of obesity surgery (also known as bariatric surgery) for morbid obesity in the short-term. Relatively little is known about longer-term health outcomes, health service utilisation, medications and associated costs for people undergoing obesity surgery in Australia and how these outcomes and costs compare to those of patients who are potentially eligible but do not undergo obesity surgery.

In addition, there is Inequity of access to obesity surgery and long wait times in the public health system since most obesity surgery occurs in the private hospital system. Uninsured patients who are primarily of lower socioeconomic status and who have a higher risk of morbid obesity have more limited access to this form of treatment. Importantly, little is known about the health and cost implications of the long waiting periods for initial obesity surgery, or the impact of reducing these waiting times.

The retrospective study cohort comprised of an obesity surgery operated group and a matched control group of body mass index (BMI)-age-sex-propensity score-matched 45 and Up participants who have not had obesity surgery. The CheReL facilitated this study by linking the 45& Up cohort data, and linked MBS and PBS data to Admitted Patient Data Collection (APDC), Emergency Department Data Collection (EDDC), NSW Central Cancer Registry (CCR), NSW Mental Health Ambulatory Data (MH-Amb), NSW Registry of Births, Deaths and Marriages (RBDM) (deaths) and Cause Of Death Unit Record Files (COD-URF).

This project aims to assess the characteristics, physical and mental health outcomes, costs and health service use associated with obesity and obesity surgery. Outcomes, service use and costs will be compared, preoperatively and post-operatively in participants in the 45 and Up cohort who have had obesity surgery, and compared to the control group.

Findings from this study will inform obesity surgery management as well as resource allocation decisions regarding the provision of obesity surgery in the public and private health care systems.

Exploring the role of being an overweight or obese women and how accurate self-reporting of mammographic breast screening participation is in New South Wales, Dr Kate McBride, Western Sydney University

Currently, breast cancer is a major health issue in Australia and places a substantial burden on the healthcare system. Early detection via mammography screens has been shown to reduce mortality due to breast cancer, however screening rates for free services are less than ideal in some at-risk population groups. Previous studies have shown that obesity is linked to a decreased rate of participation in mammography screens.

This study aims to establish a comprehensive and rigorous understanding of how Body Mass Index (BMI) affects participation in mammographic breast screening.

The CheReL will facilitate this study by linking self-reported screening data from the Australian Longitudinal Study of Women's Health (ALSWH) with objectively collected screening data from the BreastScreen NSW screening program from 1996 onwards.

This study aims to capitalise on these two existing data sources by examining a randomly stratified group of 13,714 women to determine the association between different variables and mammography screening. Specifically, the association between BMI and mammography screening participation over time, and recommendations for the development of potential interventions to facilitate access to mammography screening among women in the target age group. This project will also examine the accuracy of self-reported screening data in the ALSWH by comparing it to the BreastScreen routinely collected data.

Results of this study are expected to inform recommendations for future programs and development of treatments.

Evaluation of Community-based Mental Health Programs: Community Living Supports (CLS) and Housing & Accommodation Support Initiative (HASI), Associate Professor Karen R Fisher, University of New South Wales

NSW Health has implemented state-wide programs designed to support people with mental illness in their recovery from mental illness within the community. These include Community Living Supports (CLS) and Housing & Accommodation Support Initiative (HASI). The Social Policy Research Centre (SPRC) at University of New South Wales was commissioned by NSW Health to conduct an evaluation of CLS-HASI programs in relation to their objectives, including how effective and culturally appropriate these supports were for Aboriginal people.

The mixed method evaluation study included qualitative interviews with participants and stakeholders and secondary data analyses. The CHeReL facilitated the secondary data analyses by linking the CLS-HASI Minimum Data Set (individuals who entered CLS or HASI in the period 2002-2019 – 'cohort data') and that of a comparison group (sourced from the CLS-HASI program waitlists) with the following data sets: NSW Admitted Patient Data Collection (APDC), NSW Emergency Department Data Collection (EDDC), NSW Registry of Births, Deaths and Marriages (RBDM) (deaths), NSW Mental Health Ambulatory Data Collection (MH-AMB), Australian Coordinating Registry (ACR) Cause of Death Unit Record File (COD URF), and the Mental Health - Outcomes and Assessment Tool MH-OAT. The CHeReL also developed linkage with additional external datasets held by HASI program partner agencies including the NSW Department of Communities and Justice (DCJ) Housing, the NSW Bureau of Crime Statistics and Research (BOCSAR) and the NSW Corrective Services Offender Inmate Management (OIM) system.

The data linkage study will develop quantitative analysis of the linked program and outcomes data for CLS and HASI clients to measure change over time through time series analysis comparing before, during and after entry to the program. The quantitative analysis will be incorporated into health economic Markov modelling to assess program cost effectiveness. The findings from this

social policy research study are expected to assess the quality, outcomes and benefits of CLS-HASI and policy implications.

Variations in surgical outcomes in New South Wales, Professor Louisa Jorm, University of New South Wales

Australia's population is geographical dispersed and primarily located in major cities. Moreover, Australia has a unique mix of public-private hospital services with a complex funding model. It is likely that these factors promote fragmentation of health care.

The aims of this data linkage study are to quantify and characterise variations in surgical outcomes (including complications, post-discharge care, ED presentation, readmission, mortality) in New South Wales patients in relation to public versus private hospitals and payers, hospital surgical volume and geographic remoteness and the adoption of newer technologies. Specific areas of focus are cardiac, orthopaedic, thoracic, vascular, abdominal, colorectal surgeries as well as urological, neurosurgical, and gynaecological interventions.

The cohort for this study (~4.5 million people) was identified by the CHeReL from NSW hospital records and included patients with a hospital separation in NSW from July 2001 to latest available, with any of the pre-defined surgical, interventional or a procedure code. Cohort data was linked by the CHeReL to the NSW Admitted Patient Data Collection (APDC), NSW Emergency Department Data Collection (EDDC), NSW Registry of Births, Deaths and Marriages (RBDM) (deaths), Australian Coordinating Registry (ACR) Cause of Death Unit Record File (COD URF) and the Australian Orthopaedic Association National Joint Replacement Registry. The Australian Institute of Health and Welfare further linked the cohort to Commonwealth datasets (MBS, PBS and National Death Index).

This retrospective population-based cohort study will explore care fragmentation, identify disparities in care and outcomes by subgroups including diagnoses, age, social class and indigenous status. By focusing on three key areas — the interplay of public and private sectors, geographic dispersion and centralisation of services, and adoption of new surgical technologies – the study will provide a comprehensive picture of surgical care outcomes in Australia.

Digital vs Screen-Film Mammography in Breast Cancer Screening: Impact on Screen-Detected and Interval Cancers' Detection, Characteristics and Treatment, Dr Katy Bell, University of Sydney

Breast cancer is the most common cancer in women in the world and in Australia. Screening programs aim to reduce cancer mortality rates through earlier detection and early treatment of malignancies. To this end, population-wide mammography screening program was implemented in Australia in 1991. In recent years, full-field digital mammography (FFDM) has replaced screen-film mammography (SFM) throughout Australia. The effect of this move on health outcomes including screen-detection rates and interval cancer rates remains unclear.

This data linkage study aims to measure the effect of this change in practice on health outcomes through time trend analyses of individual patient data on breast cancer screen-detection rates and interval cancer rates before, during, and after the roll out of digital mammography in NSW.

Two cohorts were examined through this study; cohort A - all women ever screened and cohort B - all women ever diagnosed with breast cancer. The CHeReL facilitated this study by linking data from Breast Screen NSW, NSW Central Cancer Registry (CCR), NSW Admitted Patient Data Collection (APDC) and NSW Registry of Births, Deaths and Marriages (RBDM). Using linked data the researchers will capture women's journeys from screened/unscreened to cancer/no cancer to treatment/no treatment to dead/alive and thus create a patient journey from screening to diagnosis to treatment to death. An analysis of trends in the distribution of available tumour characteristics (such as stage, histology, and grade) is included in this study.

The project findings are expected to provide important information in relation to the incremental benefit and overdiagnosis attributable to changing from film to digital mammography in NSW.

Epidemiology, characteristics and management and outcomes of injury in individuals aged 0-25 in NSW, Associate Professor Julie Brown, Neuroscience Research Australia

Globally, traumatic injury is the leading cause of mortality, hospitalisation and ongoing disability in children over the age of one and in adults up to the age of 45. In Australia, national child injury hospitalisation and death rates have not decreased in the past ten years. The effects of traumatic injury can be devastating and long-lasting, with repercussions for the patient, their family and their community.

The investigators of this project aim to establish a program of population-based injury research focused on children and young people aged 0-25 years. Access to population-based injury data, and analysis will inform current and proposed injury prevention research, provide opportunities to analyse the effectiveness of injury prevention initiatives, allow evaluation of injury management and outcomes and to assess the impact of trauma management guidelines.

The study cohort includes all injured children and young people age 0-25 admitted to a NSW hospital during the study period or those who died as a result of injury sustained during the study period. The CHeReL facilitated this population-based retrospective cohort data linkage study by extracting cohort data from the Admitted Patient Data Collection (APDC) and linked to matching records in the APDC and NSW Registry of Births, Deaths and Marriages (RBDM) and Cause of Death Unit Record File (COD URF).

The study outcomes are expected to provide a much-needed baseline on which an evidence-based and strategic approach to reducing the burden of injury to children and young people in NSW can be developed. Importantly, this program of work will provide this for both injury prevention and injury management actions, and provide much needed resources for injury prevention regulators, policy makers and advocates, as well as health professional education, and trauma service planning.

Improving personalised decision making for oncology patients using data mining and rapid learning techniques, Associate Professor Lois Holloway, Liverpool Hospital, NSW

The rapid development and use of novel technologies and treatments for cancer, the difficulties of randomised clinical trials (RCT) in this area and the relatively small numbers of RCT patients as a proportion of all patients (3%) have all contributed to a growing evidence gap in cancer treatment decisions, particularly in radiation oncology. However, there is a huge amount of routine electronic clinical data collected on cancer treatments that could provide further evidence, complementing Randomised Clinical Trials data, to help support optimised clinical decisions.

The overall objective of this retrospective study is to develop and assess a data mining approach to radiotherapy data, wherein data from previous treatments are stored at the local institutions. Combined models are developed based on parameters determined from each of the local institution datasets to better inform clinicians and future patients. The project aims to test, use and further develop the distributed learning approach, initially for lung, head and neck and prostate radiotherapy treatments.

Patients identified in one of the 5 local radiotherapy datasets (i.e. patients with lung, head and neck or prostate cancer who have received radiotherapy) from five identified clinical sites in NSW formed the cohort and were linked by the CHeReL to NSW Cancer registry (NSW CR), NSW Clinical Cancer registry (NSW ClinCR), NSW Admitted Patient Data Collection (APDC), and NSW Registry of Births, Deaths and Marriages (RBDM) and Cause of Death Unit Record File (COD URF).

For each of the clinical sites an outcome prediction model will be developed based on available patient, disease and treatment characteristics using

distributed learning and then validated. These models are expected to provide clinicians with additional clinical evidence where clinical trial evidence is limited or lacking, and improve the treatment decision and prognosis information available to patients and clinicians.

Impact of donor, recipient and transplant-related factors on kidney transplant and patient outcomes in Australia: The REnal TRansplant-related factors and Outcomes (RETRO) study, Associate Professor Germaine Wong, The Children's Hospital at Westmead

Newer ways of matching donor kidneys to recipients have been developed and have the potential to revolutionise kidney transplantation but the evidence supporting their clinical use remains limited. This data linkage project aims to create and use linked datasets to evaluate the evidence for an alternative efficient method of utilising donor kidneys in Australia. To provide this evidence, detailed immunological and molecular data on the donors, recipients and potential transplant candidates from the National Organ Matching System (NOMS) were linked to the data from the Australia and New Zealand Dialysis and Transplant Registry and other health related datasets.

All recipients of kidney transplants and their respective donors as well as patients on the transplant wait list constituted the study cohort for this retrospective study. The CHeReL facilitated this study by linking the two cohort datasets and administrative data from the NSW Cancer registry (NSW CR), NSW Admitted Patient Data Collection (APDC), and NSW Registry of Births, Deaths and Marriages (RBDM deaths) and Cause of Death Unit Record File (COD URF), ACT Admitted Patient Collection (APC), ACT Cancer Registry (ACT CR) and ACT BDM Death Registrations.

Using existing genetic, immunological and healthcare data, this project aims to determine whether novel donor kidney allocation model utilising newer technologies may lead to better health outcomes compared to the current allocation model.

An evidence-based approach to improving outcomes and reducing hospital-acquired complications in patients with blunt chest injury: Chest Injury bundle of care Protocol (ChIP), Professor Kate Curtis, University of Sydney

Blunt chest injury resulting in rib fractures and hospital admission are rising in Australia. Failure to effectively treat blunt chest injuries (e.g.broken ribs) leads to hospital acquired complications: pneumonia, respiratory failure and

unplanned intensive care admissions. These outcomes result in patient suffering and unnecessarily high healthcare costs.

This pre-post data linkage study will firstly determine incidence and outcome of patients with blunt chest injury in six NSW hospitals. The impact of implementing an evidence-based, multidisciplinary early notification mechanism and a chest injury care bundle protocol (ChIP), on the clinical and health service outcomes for patients with isolated blunt chest injury will be evaluated across three intervention sites and compared to three non-intervention sites. The researchers will also determine the rate of uptake of Chest Injury Protocol and identify any facilitators and barriers associated with the uptake of the protocol to inform wider implementation. Rates of non-invasive ventilation pre-and post-implementing the ChIP protocol compared to contemporaneous rates with current standard practice will be estimated

The Study cohort includes adults admitted with blunt chest injury via Emergency Department. The CHEREL facilitated this study by extracting cohort data from the NSW Admitted Patients Dataset collection (APDC) using identified diagnosis/procedure codes. Site medical records and “Patient with Acute Condition for Escalation” (PACE) activation data for the cohort were linked by the CHeReL to matching records in the APDC and Activity Based Funding (ABF) data.

This translational research study is expected to test a sustainable and evidence-based bundle of care protocol to reduce hospital-acquired complications associated with poorly managed chest injuries and improve the quality of care and patient outcomes.

Informing women about overdiagnosis in breast cancer screening: Effects on screening program participation, Professor Kirsten McCaffery, University of Sydney

Mammography screening can reduce breast cancer mortality. However, inconsequential disease that may never present clinically in a woman’s lifetime can also be detected by screening, leading to overdiagnosis and overtreatment. This is considered a serious and important harm of screening. There is a lack of evidence regarding how information on overdiagnosis affects women’s views and decisions about breast screening.

The aim of this BreastScreen data linkage project is to assess the effects of information about overdiagnosis on participation in the BreastScreen program. Specific outcomes include informed decision making, breast screening participation, and psychosocial outcomes over a period of 2 years.

The Breast Cancer Screening Information Study is a community-based, parallel-group, randomised controlled trial in NSW. Participants were randomly assigned to either the intervention decision aid (comprising explanatory and quantitative

information about overdiagnosis, breast cancer mortality reduction, and false positives) or a control decision aid (including information about breast cancer mortality reduction and false positives). Self-reported study outcomes were assessed during four follow-up telephone interviews over a period of two years post-intervention.

The data linkage substudy included trial participants who provided written consent for linkage to their personal data held by BreastScreen NSW. The CHeReL linked the participant consent dataset (a database including all study participants who provided written consent for this data linkage) to the mammography uptake data from the BreastScreen program records and thereby enhanced the reliability and validity of the data for this important study outcome.

The overall study findings will provide important information on the effects of including information about overdiagnosis of breast cancer in a decision aid (evidence-based information resource) for women aged around 50 years who are considering mammography screening.

Surgical Care of Older PEople (SCOPE), Dr Lara Harvey, Neuroscience Research Australia.

Over half of all hospitalisations involving surgery in Australia are for older people, and there is evidence that there are wide variation in rates of surgical procedures being performed across geographical locations. Despite this, little is known at the population level about the hospitalisation experience and outcomes for older people who are hospitalised for a surgical condition.

This retrospective cohort data linkage study will examine hospitalisations for people aged 50 year and over, admitted to a NSW hospital for a surgical condition, during the ten year period 2007- 2016. Specifically, the project will provide hospitalisation profiles, examine trends, and quantify health service use and outcomes for this cohort. The project also aims to explore clinical variation in the care of older people for four high-volume clinical conditions, common in older people - cholecystitis, pancreatitis, appendicitis, and bowel obstruction. Factors that may contribute to unwarranted clinical variations will be explored and costs of differing models of care for the four selected surgical conditions will be estimated as part of this study.

The CHeReL facilitated this study by identifying the cohort individuals in NSW Admitted Patients Dataset collection (APDC) using identified diagnosis/procedure codes and linking to NSW Admitted Patients Dataset collection (APDC), Registry of Births, Deaths and Marriages (RBDM Deaths) and the Cause of Death Unit Record File (CODURF).

The research findings are expected to provide better understanding of the changing surgical profile in older people in NSW and this information can be

used to identify priority areas of research as well as inform policy and models of care in NSW and beyond.

Survey of High Impact Psychosis (SHIP), Professor Vera Morgan, University of Western Australia

Physical morbidity, especially cardiometabolic disease, and premature mortality are elevated in people with psychotic illness. However, few studies have examined longitudinally the relationship between comprehensive clinical and other characteristics and mortality/morbidity in a large, representative sample of people with a range of psychotic disorders. These data are essential for understanding risk for avoidable mortality/morbidity in this population and informing services on appropriate and timely interventions.

The Survey of High Impact Psychosis (SHIP) data linkage study aims to estimate rates of mortality and morbidity with people with psychotic conditions, overall and by different conditions. Additionally, risk factors for increased morbidity and mortality in this population, risk prediction instruments for cardiovascular disease and costs associated with the additional morbidity and mortality will be estimated.

The SHIP is a comprehensively characterised and nationally representative sample of people with psychotic disorders. This retrospective study involves linking data of consented individuals from the SHIP cohort to morbidity, ED and cancer registry datasets in multiple Australian states and to the National death Index. For the NSW component, the CHeReL linked the cohort data to NSW Admitted Patient Data Collection (APDC), NSW Emergency Department Data Collection (EDDC) and the NSW Central Cancer Registry (NSW CCR).

Findings from this important study are expected to fill the knowledge gap on mortality and morbidity in people with psychotic disorders and help to address health inequities in this population.

The data linkage sub-study of the Expanded PrEP Implementation in Communities study (EPIC NSW), Professor Andrew Grulich, The University of New South Wales

For Gay and Bisexual Men (GBM) who are at high risk of HIV infection, pre-exposure prophylaxis (PrEP) against HIV is likely to represent the most effective means of HIV prevention. PrEP involves a combination of antiretrovirals taken on an ongoing basis to prevent HIV infection.

Despite the proven very high individual-level efficacy of PrEP, little is known about the population-level effectiveness of the implementation of PrEP. The

Expanded PrEP Implementation in Communities (EPIC-NSW) study was a non-randomised implementation research project that aimed to assess the incidence of HIV among study participants and measure the population-level impact of the rapid roll-out of PrEP on HIV diagnoses among GBM in NSW over a two-year period.

The data linkage sub-study aims to identify notifications of HIV and Sexually Transmitted Infections (STI) in NSW to optimise the ascertainment of these diagnoses in EPIC-NSW study participants.

The cohort for this prospective data linkage sub-study includes EPIC-NSW study participants who have provided their written consent for data linkage. The CHeReL facilitated this study by linking cohort data from the EPIC-NSW database to the NSW HIV Register and the NSW Notifiable Conditions Information Management System.

This data linkage will optimise the ascertainment of HIV and STI diagnoses arising from EPIC-NSW study participants and thus contribute to the overall aims of the study.

Investigating cardiovascular morbidity after injury and potential therapeutic interventions to mitigate disease, Associate Professor Janine Duke, University of Western Australia

Injury and trauma triggers systemic responses and the impact of these systemic responses can last long after the injury, leading to poorer future health for these individuals. In particular, cardiovascular dysfunction appears to be more common after injury. There is limited evidence that beta-blockers (a class of medications commonly used to treat cardiovascular disease) may be useful in reducing cardiovascular risk after injury.

This study will use linked administrative data to investigate whether individuals have greater morbidity after injury and whether specific medications reduce this morbidity. The study will also estimate the economic cost of injury and injury associated morbidity.

Participants from the 45 and Up Study who were hospitalised with an injury between survey completion and 2018 were the cases and those who completed the survey but had no such hospitalisation formed the control group for the case-control analysis. The CHeReL linked cohort data from the 45 and Up survey (linked to Medicare Benefits Schedule and Pharmaceutical Benefits Schedule) to the NSW Admitted Patient Data Collection, and the NSW mortality data (NSW Registry of Births, Deaths and Marriages and Australian Coordinating Registry Cause of Death Unit Record File).

The study will compare the risk of post-injury morbidity (particularly CVD morbidity) and hospitalisation rates between the cohort and control group after adjusting for other factors and assess the economic cost of injury and subsequent morbidity. Within those with injuries, the study will determine if beta blocker medication use reduces the risk of post-injury CVD hospitalisations.

The knowledge gained from this project will be translated into improved clinical management of those with injuries, improving the well-being of patients with the aim to ultimately reduce post-injury cardiovascular admissions.

Quantifying the health and economic impacts of maintaining/adopting a healthy lifestyle on stroke survivors, Dr Wenbo Peng, University of Technology Sydney.

In Australia, nearly one million people are predicted to live with stroke by 2050 and the total burden of disease cost is estimated to be $49.3 billion. Lifestyle risk factors for stroke, including obesity, smoking, alcohol-dependence, and physical inactivity, account for approximately 80% of the risk of recurrent stroke of all types. Clinical Guidelines for Stroke Management have recommended lifestyle modifications for recurrent stroke prevention.

The overall aim of this project is to quantify the use of health services, health outcomes, and medical costs of Australian stroke survivors who maintain or adopt a healthy lifestyle. The researchers will profile stroke survivors who maintain or adopt a healthy lifestyle, compare their health service use with those who do not, and ascertain differences in medical costs (including Medicare and out-of-pocket costs) and health outcomes (including mortality rate) between the two groups.

The Centre for Health Record Linkage (CHeReL) facilitated this study by linking retrospective cohort data (i.e. 45 and Up study participants who had self-reported a stroke experience) from the 45 and Up Study to three routinely collected datasets - the NSW Registry of Births, Death and Marriages, the Australian Coordinating Registry Cause of Death Unit Record File, and the NSW Admitted Patient Data Collection while the Australian Institute of Health and Welfare provided Medicare Benefits Schedule and Pharmaceutical Benefits Schedule data via the Sax Institute.

The findings of this project may help empower stroke survivors to make necessary lifestyle changes to reduce their risk of recurrent stroke, aid clinicians and policy-makers in determining whether lifestyle change is a cost-effective care option for stroke rehabilitation, and pave the way to a stronger focus on secondary stroke prevention via lifestyle modifications.

Understanding potentially preventable hospitalisation among older Australians with chronic conditions, Associate Professor Megan Passey, University of Sydney

The number of potentially preventable hospitalisations (PPH) among older Australians continues to grow both internationally and in Australia. The overall aim of this project is to generate an evidence base identifying modifiable factors driving PPH admissions for chronic conditions amongst older community dwelling people.

The cohort for this study included eligible (community dwellers aged ≥ 45 years) patients with selected chronic PPH unplanned admissions from three NSW Hospitals. The CHeReL linked identified cohort (DaPPHne dataset) to their records in the NSW Admitted Patient Data Collection, NSW Registry of Births, Death and Marriages (Death registrations), the Australian Coordinating Registry Cause of Death Unit Record File and NSW Emergency Department Data Collection.

The data linkage substudy aims to develop models to predict the preventability of individual admissions using routine administrative data; investigate how additional items (e.g. measures of self-rated health) can improve the prediction of preventability; and investigate factors that influence longer-term outcomes following admissions classified as preventable and non-preventable, to explore and understand patient help seeking processes, experience of disease(s) management, and the contributions of social and personal factors to preventable admissions. Clinician assessment of the preventability of each admission will enable comparisons between admissions classified as preventable and not preventable.

The research findings are expected to improve measures of health system performance and develop effective interventions to reduce preventable admissions.

Investigating vaccine safety via cross-jurisdictional data linkage of the Australian Childhood Immunisation Register (ACIR) with hospital morbidity data - New South Wales (NSW) component, Associate Professor Michael Gold, University of Adelaide, South Australia

The success of Australia's immunisation programs relies not only on optimising immunisation coverage but also ensuring immunisation safety, which includes the recognition of adverse events following immunisation.

The overarching aim of this project is to establish whether linked health data from multiple Australian jurisdictions (immunisation data linked to outcomes data (hospital separations and emergency department presentations) can be used in the assessment of vaccine safety.

A specific objective of the vaccine safety surveillance project involves determining whether the linked data can identify recognised serious and life-threatening adverse events following immunisation (AEFI).

For the NSW Component, the CHeReL linked records from NSW Admitted Patient Data Collection and the Emergency Department Data Collection for all NSW children aged less than seven years at admission to a public hospital between July 2003 to June 2013 and/or presentation to an emergency department presentation between January 2005 to June 2013. The Australian Institute of Health and Welfare will link to matching records in the core dataset for linkage Australian Childhood Immunisation Register (ACIR). Similarly, ACIR data will be linked to health outcomes data from other jurisdictions and the researchers will apply conventional epidemiological methods to demonstrate whether vaccine safety issues can be confirmed or refuted.

The findings from this project could provide a mechanism to identify potential safety issues following immunisation and allow risk-benefit evaluation of each vaccine.

Parenthood in patients receiving dialysis or kidney transplantation: A national study of perinatal risks and outcomes through population record linkage, Associate Professor Shilpanjali Jesudasan, The University of Adelaide, South Australia

End-stage kidney disease (ESKD) is a serious health problem that can affect people of childbearing age. Despite reduced fertility and often substantial co-morbidity, many patients receiving renal replacement therapy (RRT; dialysis or a kidney transplant) do have babies. Women with ESKD experience high rates of adverse pregnancy outcomes and over half of the babies born to these mothers are born prematurely. Little is known about the outcome of these babies in the immediate perinatal period and into early childhood.

The aim of this project is to utilise existing perinatal, hospital, birth, death and renal registry data, to explore the outcomes of babies born to parents receiving RRT compared to the general population.

For this cross-jurisdictional study, state and territory-based births record data of babies and their mothers during 1991-2013 will be linked with other existing population-based datasets and with ANZ Dialysis And Transplant Registry (ANZDATA) dialysis or transplant (RRT) patients using local linkage organisations, to create a cross-jurisdictional dataset for analysis. The RRT patients in ANZDATA linked to perinatal or birth data constitute the RRT cohort and all non-linked perinatal data formed the non-RRT cohort.

For NSW, the CHeReL linked the ANZDATA Registry, the NSW Perinatal Data Collection, Neonatal Intensive Care Units' Data Collection, the ACT Maternal Perinatal Data Collection, NSW and ACT Admitted Patient Data Collection, ACT

Emergency Department Data Collection and the NSW and ACT Births and Deaths registry.

The linked dataset will allow researchers to identify the RRT Cohort, assess birth rates in the cohort, and examine the association between RRT factors and pregnancy outcomes, preterm delivery, antenatal events, delivery complications and perinatal outcomes. The study will also assess longer term morbidity and socio-economic burden of mothers with end-stage renal failure, compared with non-RRT cohort and women with other chronic diseases.

Using data linkage approaches, this study will provide evidence to inform clinical care and improve management of patients who are considering or are faced with parenthood whilst receiving RRT therapy.

The Health Impact and Economic cost of Residential Fires in New South Wales, Dr Kathy Tannous, Western Sydney University

In most western industrial countries, most of the fire deaths and a high percentage of fire-related injuries occur in the home. According to Fire & Rescue NSW (FRNSW), a total of 23,766 residential fires, were reported in New South Wales between 2010 and 2015, and survey data indicates that a larger number of fires are likely to have gone unreported.

This retrospective cohort study aims to determine the number of residential fires and their associated injuries and fatalities, both reported and unreported, in NSW during 2005-2015. This will be undertaken by examining reported fire incidents from FRNSW, ambulance service use, health service use (emergency and hospital admissions), and mortality data for people who had fire incident related injuries in that period. The study will utilise linked data to determine the number of injuries and fatalities, by mechanism, profile, and health service utilisation over this period and quantify the economic costs of residential fires to FRNSW, the healthcare system, and the wider community.

The study cohort comprised of residents who had experienced a residential fire identified in eight data sets: the Australian Incident and Report System (FRNSW AIRS); NSW Ambulance Computer Aided Dispatch; NSW Ambulance electronic Medical Records; Patient Health Care Record; NSW or ACT Admitted Patient Data Collection, NSW Statewide Burn Injury Service Data; NSW Register of Births, Deaths and Marriage; and Cause of Death records. Demographic information was extracted from FRNSW AIRS Data Linkage was carried out by the CHeReL for residents of NSW that had experienced residential fire and linked to the for residents of NSW that had experienced residential fires and linked to matching records in the other NSW and ACT health-related datasets.

The research will provide a better understanding of number, mechanism, nature, spatial variation, and risk factors of injuries and fatalities following residential fires and their economic impact. This information will be used to identify priority

stages for research as well as inform and influence policy and planning in NSW and beyond.

Recidivism, health and social functioning following release to the community of NSW prisoners with problematic drug use, an evaluation of the Connections Program, Professor Elizabeth Sullivan, University of Technology Sydney

The rising rate of adult incarceration in Australia is a major public health problem with high rates of return to custody, morbidity and mortality experienced by inmates, especially those with problematic drug use. The NSW Connections Program has provided targeted individualised support at all adult correctional centres across NSW for inmates with problematic drug use in their transition post release to the community.

This project will evaluate the Connections Program and determine if the model of care reduces recidivism, mortality and improves the health of patients on the Connections Program. Furthermore, it will examine the impact of the program on perinatal and infant outcomes for inmates who recently became a new mother and on their infants.

The cohort for this retrospective record linkage study included all patients in the Connections program database during the period 2008-2015. The CHeReL linked the Connections data to the NSW Admitted Patient Data Collection (APDC), Emergency Department Data Collection (EDDC), Mental Health Ambulatory Data Collection for hospital and emergency department admissions and ambulatory mental health care episodes, to NSW Bureau of Crime Statistics and Research Re-offending database for offence information and recidivism; to Health Pharmaceutical Drugs of Addiction System for opioid substitution therapy information; and to Registry of Births, Deaths and Marriages (RBDM) and Cause of Death Unit Record File to identify mortality outcomes.

For the parents sub-study, the Connections dataset was linked by the CHeReL to RBDM Births and the birth registrations were linked to NSW Perinatal Data Collection (PDC), Perinatal Death Record, APDC and EDDC to examine maternal outcomes for women on the Connection Database and infant outcomes for all mothers referred to the Connections Program.

This study will provide a methodology for ongoing monitoring of the Connections Program; and provide evidence as to whether the Connections Program should be trialled more widely in the prison system.

Exploring the relationship between mental illness, traumatic brain injury and dementia and family and domestic violence using Text

Mining and data linkage, Professor Tony Butler, University of New South Wales

This study addresses a major public health problem in Australia - Family and Domestic Violence (F&DV) – through the innovative use of Text Mining and data linkage to better understand the relationship between mental illness, traumatic brain injury and dementia among perpetrators and victims and FDV incidents, recidivism and judicial outcomes.

The researchers have earlier accessed the police's written text narratives of F&DV events which occurred between 2005 and 2016 in New South Wales (COPS data) and demonstrated the feasibility of Text Mining from COPS narratives to identify the mentions of mental illness, traumatic brain injury and dementia among the persons of interest (perpetrators) and victims.

The proposed study aims to examine the veracity of these 'mentions' extracted from the COPS narratives using Text Mining through analysis of a linked dataset. The CHeReL facilitated the study by linking the COPS data, NSW Health diagnostic data from Admitted Patient Data Collection and Emergency Department Data Collection, mortality data from NSW Registry of Births Deaths and Marriages and ACR Cause of Death Unit Record File and records from NSW Bureau of Crime Statistics and Research Re-Offending data (BOCSAR ROD) data. Linkage of the COPS and NSW Health diagnostic data also allows the researchers to examine the proportions of the F&DV victims and perpetrators who were diagnosed with mental illness, traumatic brain injury or dementia and compare the characteristics of perpetrators and victims and examine features of FDV events in those with and without a diagnosis of these conditions.

Research findings are expected to offer direct benefits to the NSW mental health, police and corrective service systems in terms of identifying the health risks of domestic and family violence.

The DRIVE Study: where are they now? 12 years of follow-up for 20,000 novice drivers in NSW, Professor Rebecca Ivers, The George Institute for Global Health

Reliable evidence about the causes of young driver injury crashes is required if the substantial burden imposed by these injuries on young people in Australia and internationally is to be reduced. The primary aim of the DRIVE Relinkage study is to identify the direction and size of associations between postulated risk factors and the incidence of young driver crash and injury. The secondary aim is to determine whether factors associated with increased risk of driver injury are comparable across different socioeconomic, ethnic and cultural groups.

The DRIVE Study recruited and surveyed 20,822 novice drivers, aged 17-24 years, during 2003-2004, with a follow-up resurvey of some participants after a

year. In the DRIVE linkage study, survey data was linked with up to approximately 2 years of follow-up licence, offence, crash and health data (from participant's first point of licensing to 31 December 2005). The original DRIVE study investigated the importance of potential determinants of motor vehicle crashes and injuries among young drivers. The DRIVE Relinkage study aims to extend the original study by examining linked hospital, crash and death data over a 12-year follow-up period enabling researchers to investigate long-term effects of novice driver behaviour and attitudes

To facilitate this study, the CheReL linked cohort data to records related to motor vehicle accident admissions from the NSW Admitted Patient Data Collection, mortality data from NSW Registry of Births Deaths and Marriages (Death registrations) and ABS Cause of Death of Unit Record File (COD-URF), and crash data from the Centre for Road safety's CRASHLINK.

Findings to-date from the DRIVE study have been fundamental in informing risk factors for young driver crashes in NSW and the extended study is expected to provide information on the long-term effects of novice driver behaviour and attitudes.

Cancer and Reproductive Outcomes for Women: a population-based cohort study, Professor Elizabeth Sullivan, University of Technology, Sydney

Cancer treatment has implications for subsequent pregnancies. Moreover, as women delay childbearing until a later age, an increasing number of women are diagnosed with cancer around the time of pregnancy and this presents unique challenges with clinical management and burden for both the mother and baby. Cancer is the second most common cause of death among women of childbearing age. However, there is a lack of epidemiological data on reproductive outcomes in cancer or the role of reproduction in cancer outcomes.

To address the evidence gap, this project investigates the inter-associations between cancer and pregnancy, to better understand the birth outcomes and survival of women with pregnancy associated cancer (PAC); and cancer survivors who subsequently give birth. This study will provide information on pregnancy complications, and the maternal, perinatal and infant outcomes of women giving birth with PAC and in women who conceived and gave birth subsequent to their cancer diagnosis. This study will also examine the impact of giving birth on survivorship and morbidities of women with cancer.

The project consists of two population-based cohort studies, linked by the CheReL to multiple routine data collections in NSW over time, including the NSW Cancer Registry , NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, Perinatal Data Collection and Perinatal Death Reviews database, Neonatal Intensive Care Units' Data Collection, NSW Register of Congenital Conditions, NSW Mental Health Ambulatory Data Collection and

NSW Register of Births, Deaths and Marriages (Death registrations) and ABS Cause of Death Unit Record Files. The characteristics and outcomes of women will be captured comprehensively through the linked datasets and compared between subgroups depending on whether they have a history of cancer or have given birth. Such understanding is the first step towards improving care and optimising outcomes associated with pregnancy associated cancer.

The D-Health Trial: Data Linkage, Professor Rachel Neale, QIMR Berghofer Research Institute

Research suggests that Vitamin D may play a role in many diseases including cardiovascular disease, diabetes, and cancer risk and survival, additional to its role in bone health. However, large population-based clinical trials are needed to determine if supplementation has health benefits.

The D-Health trial was established in 2014 to meet the need for such trials. Over 21,000 adults from the general Australian population were recruited and randomised to receive vitamin D or placebo, once per month for 5 years. The primary/secondary outcomes of this trial are mortality and cancer, although there is a wide range of other outcomes.

The data linkage component of the D-Health Trial seeks to link the trial cohort with administrative datasets from multiple Australian Jurisdictions to capture information about death, cancer, and health outcomes that frequently result in hospitalisation. For NSW and ACT, the CHeReL linked cohort data to NSW Cancer Registry , NSW Admitted Patient Data Collection, NSW Registry of Births, Deaths and Marriages (Death registrations) and ABS Cause of Death Unit Record File, ACT Cancer Registry, ACT Admitted Patient Data Collection, ACT Births, Deaths and Marriages (Death registrations) and Cause of Death Unit Record File.

The linked data will enable the parent trial to assess the effect of supplementing Australians aged 60-84 years with vitamin D for 5 years on key health outcomes. The projects also aims to contribute to individual patient data meta-analyses to enable analysis of the effect of vitamin D supplementation on less frequently occurring health outcomes.

Findings from the analysis of linked data are expected to provide robust estimates of effect of Vitamin D supplementation for a range of health conditions.

Melanoma Patterns of Care Study 10 year follow up study, Professor Anne Cust, University of Sydney

The Melanoma Patterns of Care Study (MPOC) is a population-based, observational study based on doctors' reported clinical management of melanoma patients diagnosed with an in-situ or invasive primary melanoma over a 12-month period from October 2006 to 2007.

The aim of the data linkage study is to collect 10-year follow-up outcomes for melanoma patients in the Melanoma Patterns of Care (MPOC) study to determine the risk of recurrence and death associated with different aspects of melanoma diagnosis, clinical management and patient and histological factors. The study also aims to assess the risk of new primary melanoma and other cancers and determine whether planned follow-up, patient and histopathological factors and compliance with clinical practice guidelines are related to the stage and the other characteristics of new primary melanoma, or occurrence of other type of cancer.

Data was sourced from the NSW Cancer Registry (NSWCR) master database and data variables extracted from pathology reports held by the NSWCR. Data linkage was performed by the CHeReL to the NSW Admitted Patient Data Collection, NSW and ACT Registry of Births, Deaths and Marriages (Death registrations), ABS Cause of Death Unit Record File and The Melanoma Institute of Australia Medical Record Database.

Obtaining follow-up data on recurrence and vital status for MPOC participants provides a unique opportunity to inform clinical practice guidelines and impact on patient care in Australia and internationally. The information will also add to ongoing research on the aetiology of melanoma and whether there are shared underlying risks for different cancer types, based on genetic and treatment related factors.

Medically Assisted Reproduction: The role of IVF, ovulation induction and subfertility on Reproductive and Infant Outcomes, Professor Georgina Chambers, University of New South Wales

One in 25 children is conceived in Australia using Assisted Reproductive Techniques (ART). A further unknown proportion is conceived using prescribed medications in ovulation induction. The lack of conclusive findings on the role of these medically assisted fertility treatments on reproductive outcomes and the health outcomes of the children has created an increasing important gap in evidence to guide clinical practice.

This project aims to determine the number and proportion of children conceived by medically assisted fertility treatments, thus providing evidence on the role and contribution of ART and non-ART treatments to clinical care, family formation and population demographics in Australia. The project will also estimate reproductive and obstetric outcomes of women following fertility treatments and quantify the risk of adverse health outcomes in children under two years conceived through fertility treatments and common variants of ART practice compared to spontaneously conceived children.

This retrospective cohort analysis was facilitated through data linkage of NSW and ACT administrative datasets carried out via the CHeReL followed by linking of Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Schedule datasets by the AIHW. The CHeReL linked cohort data from the Australian and New Zealand Assisted Reproductive Technology Database (ANZARD) to NSW and ACT Perinatal Data Collections (PDC), NSW & ACT Registries of Births, Death and Marriages death registrations, NSW Register of Congenital Conditions, NSW & ACT Admitted Patient Data Collection, Cause of Death Unit Record File.

Data Linkage will enable validating the ANZARD database against the MBS and the NSW/ACT PDC. Findings from this study are expected to provide important evidence for advising patients, clinicians, and policy makers on the role of medically assisted fertility treatments in clinical practice and their safety.

Maternal and environmental risk factors for congenital conditions in New South Wales, Australia, Dr Catherine Chojenta, University of Newcastle, NSW

The aim of this project is to examine the maternal sociodemographic and physical environment in relation to congenital conditions in NSW and to examine hospital use for congenital conditions. For this project, one condition (gastroschisis) and one major contributing factor (maternal diabetes), both of increasing prevalence in NSW, were chosen as a case study by the researchers. Specifically, a matched case-control study to examine the risk factors for gastroschisis and the relationship between maternal diabetes and congenital conditions will be examined.

To achieve these aims, a population-based data linkage study will be conducted; five years of available data (2011-2015) on the Register of Congenital Conditions RoCC was linked to NSW Perinatal Data Collection the PDC by the CHeREL. All births recorded on the PDC for the five-year period (approximately 500,000 births) and all available information regarding the mother's sociodemographic risk factors will be examined.

The proposed study will make a major contribution to knowledge by using large scale surveillance data to examine both the sociodemographic and physical environment in relation to congenital conditions in NSW. The project will examine any geographical clustering, providing critical information regarding the environmental risks for congenital conditions. Clustering of sociodemographic factors will also be considered in order to examine unique associations between factors and risk for congenital conditions.

Through this study, the researchers hope to develop evidence to emphasise the need for an optimal maternal and physical environment in order to reduce the rates of congenital conditions.

Genetic contributors, clinical course and pharmacogenomics of Bipolar Disorder using data linkage in NSW, Associate Professor Janice M Fullerton, Neuroscience Research Australia

Bipolar disorder (BD) is a major mood disorder characterised by periods of mania and depression and is ranked in the top 20 most disabling disorders globally.

The overarching aim of this project is to gain a greater understanding of the causes and treatment of bipolar disorder (BD), examine the clinical, genetic and pharmacogenomic aspects of BD risk and response, as well as the genetic determinants of general medical comorbidities.

In the first phase, individuals already participating in the Sax Institute's "45 and Up" Study cohort were linked to NSW administrative health data (Admitted Patient Data Collection, Emergency Department Data Collection, Mortality Data (Registry of Births, Deaths and Marriages, and ABS Cause of Death Unit Record File), and Mental Health Ambulatory Data Collection) via the CheReL and to Commonwealth Pharmaceutical dispensing and Medicare data (PBS and MBS) through the Sax Institute to identify participants likely to have BD. In the next phase, 3,500 individuals with a prpbable BD diagnosis will be invited to participate in a BD substudy. The substudy participants will complete a questionnaire on lifestyle, clinical symptoms and treatment experience, and provide biological (blood) samples for genomic and biomarker analysis.

The researchers aim to characterise the genetic determinants of BD risk and severity, and identify key genes and pathways for treatment response, informing future biomarkers for personalised medicine. Finally, the study will examine the clinical and genetic relationships between BD and common comorbid conditions and quantify the long-term outcomes of people with BD.

Linked futures: maternal mental health and children's development through linked longitudinal data, Professor Rosa Alati, School of Public Health, Curtin University

Existing evidence suggests that exposure to prenatal depression, anxiety, and stress increases the risk of behavioural problems and reduces cognitive ability in early childhood. There is, however, limited literature on the longer-term behavioural and cognitive outcomes among offspring prenatally exposed to depression, anxiety, and stress. Further evidence of the potential for such relationships is needed to inform best practice decisions about treatment.

The aim of this project is therefore to assess the impact of maternal prenatal mental health problems and psychotropic medications on behavioural and educational trajectories of adolescent offspring in the general population.

The longitudinal cohort study is based on administrative data and includes all individuals born (live births) in NSW in 2003-2005, and their mothers and fathers. The CHeREL facilitated the study by linking multiple NSW data collections to create a birth cohort to which the Commonwealth datasets Medicare Benefits Schedule and Pharmaceutical benefits Schedule were linked by the AIHW for the period 2003-2017. The cohort data was linked by the CheReL to Perinatal Data Collection, Admitted Patient Data Collection, Mental Health Ambulatory Data Collection, NSW Registry of Births, Deaths and Marriages Birth and Death registrations, the National Assessment Program – Literacy and Numeracy, Australian Early Development Census (2009), Emergency Department Data Collection, and the Neonatal Intensive Care Unit Data Collection.

By utilising administrative health data, the researchers have created the first big data asset of its type in this field, with the capacity to clearly demonstrate the broader and longer-term neurodevelopmental outcomes resulting from such exposure in terms understood by strategic health planners, clinicians, and the public.

The burden, costs and outcomes of firearm injury in New South Wales, Prof Natasha Nassar, The University of Sydney

Firearm injuries have a substantial impact on the health and safety of populations. These injuries can be regarded as unintentional (or accidental) or intentional (due to self-harm, or assault). There is limited data on healthcare use and outcomes, especially long-term outcomes of firearm-related injuries in Australia. This information is important for those affected by firearm injuries and their families, and for policy makers.

This population-based record-linkage cohort study aims to investigate the burden of firearm injuries and describe the extent, and longer-term outcomes associated with firearm-related injury in NSW.

The study cohort was defined as registrations with codes indicating firearm injury in hospital admission data, emergency department, and mortality data since 2002. The cohort was identified by the CHeReL from NSW Admitted Patient Data collection (APDC), Emergency Department Data Collection (EDDC) and death registrations (Registry of Births, Deaths and Marriages (RBDM) and Cause of Death Unit Record File), and linked to matching records in the APDC, EDDC, RBDM and COD-URF and also to mental health data (Mental Health Ambulatory Data Collection and Mental Health Outcomes & Assessment Tools Data Collection) for each member of the cohort.

It is expected that this study will demonstrate that the immediate and long-term outcomes of firearm injuries, places a significant burden on individuals, communities and healthcare resources in NSW.

Long term follow up of participants in the ONTRAC skin cancer chemoprevention study (Oral Nicotinamide To Reduce Actinic Cancer), Professor Diona Damian, The University of Sydney

Skin cancer is Australia's most common cancer; more than half of all Australians are likely develop skin cancer by age of seventy years. Nicotinamide (vitamin B3) has been shown to be highly effective in preventing skin cancers in animal models. Invitro and animal studies suggest that nicotinamide may have also have protective effects against melanoma and against internal malignancy respectively, however, it is not yet known whether nicotinamide will have the same protective effects in humans.

The researchers of this study earlier completed a double-blinded randomised controlled trial of oral nicotinamide in otherwise healthy volunteers at high risk of nonmelanoma skin cancer (NMSC; BCC and SCC). The ONTRAC study (Oral Nicotinamide To Reduce Actinic Cancer) showed a 23% relative reduction in the rate of new NMSCs in patients randomized to receive nicotinamide tables 500mg twice daily for 12 months within the period July 2012- June 2014 as compared to the placebo group.

The aim of this retrospective cohort follow-up study is to estimate the five-year cumulative incidence of melanoma, of internal malignancy and of mortality using linked hospital and mortality data within the cohort of participants in the ONTRAC skin cancer chemoprevention study. The researchers will also assess the legacy effects of oral nicotinamide on these outcomes.

The CheReL facilitated this study by providing 5-year follow-up data on ONTRAC participants using routinely collected data available via health record data linkage. To obtain the most recent data, the CheReL linked ONTRAC cohort data to the NSW Admitted Patients data Collection (APDC) and the NSW Registry of Births, Deaths and marriages (RBDM). The follow-up linked data is also expected to help inform the design of subsequent randomised trials of nicotinamide.

Air pollution and environmental exposures and mortality and morbidity in adult Australians: a large population-based cohort study, Professor Guy Marks, The University of New South Wales

Exposure to ambient air pollution is a leading contributor to the global burden of disease. Studies in moderate to high pollution environments in North America, Europe and Asia have established an association between long-term exposure to air pollution and an increased risk of Cardiovascular Disease, respiratory diseases, lung cancer, stroke, and all-cause mortality.

This important study of Australian aged 45+ years will advance knowledge about the health effects of exposure to environmental risk factors such as air pollution, green space, noise, and influences such as urban environments,

energy transitions, social connectedness and walkability. The study will use air pollution as a priority exposure for analysis, but also aims to explore the health impact of the other environmental factors. Specifically, this study will quantify the mortality and morbidity in adult Australians which is associated with long-term exposure to air pollution. Innovative statistical methods will be used to assign air pollution exposures to the large, established 45 and Up Study cohort to determine the impact of air pollution on their health and mortality.

The study cohort includes all participants in each wave of data collection in the 45 and Up Study including the SEEF sub-study and will include prospective data from the 3rd follow-up wave. Cohort data was linked via the CheReL to hospitalisation, mortality and cancer data from NSW Admitted Patients data Collection, NSW Emergency Department Data Collection, NSW Registry of Births, Deaths and Marriages Death registrations and ABS Cause of Death Unit record File and the NSW Cancer Registry.

The overall aim of this work is to enable cost-benefit analyses for environmental planning and control by establishing valid and precise estimates for the position and shape of the air pollution exposure concentration and adverse health effect response functions for particulates and gaseous air pollutants in the low to moderate exposure range.

Adult Literacy and Aboriginal Community Wellbeing Study, Associate Professor Robert Boughton, The University of New England

Adult Indigenous Australians have low literacy levels comparable to those in the world's lowest income countries, including the poorest of sub-Saharan Africa. Over 35% of the Indigenous adult population are reported to have minimal English language literacy, with the figure rising significantly in remote areas. The 'social and economic costs' to those with very low literacy are formidable; poverty, unemployment, poor health and crime.

The aim of this study is to analyse the impact of improved adult literacy on a range of wellbeing indicators among Indigenous Australians. The study aims to compare changes in health outcomes, health service utilisation, and contacts with crime and justice before and after the implementation of the literacy program in graduates (participants) to the non-graduates (low literacy individuals who declined participation) to determine the effect of the literacy program.

Participants in the Literacy for Life Foundations adult literacy campaign and matched control group of non-participants from the same region form the study cohort. Linked data will be used to validate self-reported responses from questionnaires, and to analyse longer term changes to health and social well-being outcomes. The cohort data from Adult Literacy and Aboriginal Community Wellbeing Study dataset was linked to hospitalisation data from the NSW Admitted Patient and Emergency Department Data Collections, mortality data

from the NSW Registry of Births, Deaths, and Marriages and ABS Cause of Death Unit Record Files, crime-related data from the Bureau of Crime Statistics and Research data (BOCSAR), and other health system related data - NSW Breastscreen , NSW Pap Test registry, NSW Ambulance and Notifiable Conditions Information Management System.

This novel project is the first in Australia to investigate the effect of implementing an adult literacy campaign in low literacy Aboriginal adults.

A contemporary population study on short and long-term impact on morbidity and mortality in cardiology patients at a metropolitan tertiary hospital, Professor Leonard Kritharides, The University of Sydney

Rapid access chest pain clinics are increasing used in New South Wales to risk stratify patients who present to the emergency department with chest pain. Patients are reviewed in clinic often after further cardiac testing. Data on chest pain clinics in Australia is limited and there is no mortality data at a state level for rapid access chest pain clinics in Australia.

Using linked data, this retrospective cohort study aims to investigate the morbidity and mortality outcomes for a single-centre cohort of patients seen in the cardiology clinics at a metropolitan tertiary hospital and patients who underwent a non-contrast CT chest. The study will also investigate the incidence of fatal cardiovascular disease, and hospitalisation for non-fatal coronary disease, non-fatal stroke, atrial flutter/fibrillation according to a history of chest pain and incidental coronary calcium in non-contrast CT chest scans. Healthcare resource utilisation of patients seen in the rapid access chest pain clinics will be assessed by observing their hospital readmission rates. Potential healthcare savings by preventing hospital admissions and readmissions due to access to the rapid access clinic will be estimated.

All patients who have attended the Concord Repatriation General Hospital rapid access chest pain clinic since 2008 and hospital inpatients who had a non-contrast CT scan since 2011 (excluding those history of coronary artery diseases) constituted the study cohort. To facilitate this study, the CHeReL linked cohort data to hospital and mortality data from NSW Admitted Patient Data Collection, the NSW Emergency Department Data Collection, NSW Registry of Births, Deaths and Marriages Death registrations and ABS Cause of Death Unit Record Files datasets.

Findings from this study will provide valuable information on chest pain clinics and health outcomes of patients who are reviewed in these clinics.

Prudent advice on prevention of chronic diseases in Australia – Translating best evidence, using the 45 and up study cohort data (Program Linkage), Dr Martin McNamara, The Sax Institute

In Australia, chronic diseases (CDs) are the leading cause of ill-health and death, with 73% of deaths in 2013 due to one of 8 CDs. This retrospective cohort study series is a program of work that aims to use existing 45 and Up survey data linked to administrative datasets to examine various lifestyle factors identified in the literature as being associated with chronic diseases. To understand the burden of disease attributed to those risk factors, linked data will be analysed for risk factors, their role in the mortality and morbidity rates for the participants presenting them and their pattern of healthcare usage will be examined.

In the first instance, the researchers aim to derive evidence on the relative contribution of different risk factors to dementia prevention and progression and the impact of modifying these risk factors on dementia outcome. Dementia, a major CD, is now the leading cause of death for Australian women and the leading cause of disability in older Australians. The body of evidence for dementia is less robust, and the lack of awareness and understanding of dementia can result in barriers to its prevention and care.

For this study, the CHeReL linked the 45 and Up data to the NSW Admitted Patient Data Collection, Emergency Department Data Collection, NSW Cancer Registry, NSW Register of Births, Deaths & Marriages Death Registrations, ABS Cause of Death Unit Record File and NSW Mental Health Ambulatory Data Collection. Commonwealth data from Medicare Benefits Scheme, Pharmaceutical Benefits Scheme, National Death Index and National Aged Care Data Clearing house were linked by the AIHW.

This program of work aims to generate and translate evidence to create awareness and knowledge, to inform public health policy makers and interventionalists for a range of CDs. The researchers plan to develop a series of easy-to-use evidence-based resources to support and emphasize interventions to provide an effective and sustainable healthcare system for Australians.

Mapping correlates and predictors of youth perpetrated domestic and family violence on the Mid to North Coast of NSW, Professor Marie Hutchinson, Southern Cross University, NSW

This study forms the first part of a larger multi-study thesis on Domestic and Family Violence (D&FV) in NSW. The objective of the first phase of this study is to identify antecedents and pathways that contribute towards children and young people engaging in D&FV on the mid to north coast of NSW. Any act of violence, abuse or intimidation committed by members of a household including violence between children and their parents or carers and siblings, as well as intimate partners constitutes D&FV.

This study will examine the factors that contribute towards young people engaging in D&FV by linking data from the NSW Police Force and the NSW Ministry of Health. The researchers plan to use linked administrative data to identify the sociodemographic, family and individual characteristics of young people issued with a legal action for a D&FV offence and the association between these characteristics and severity of first offence, the risk and frequency of further offences and the risk of the young person committing other recorded non-D&FV offences in conjunction with D&FV offences. The study will also examine temporal processes and pathways for children and young people issued a legal action by the NSW Police Force.

Data pertaining to young residents (11-18 years) of mid to north coast of NSW, who were charged with a domestic violence related offence in the period July 2008-June 2018 was extracted from the COPs dataset and provided by the NSW Police to the CHeReL. The CHeREL linked the cohort data to NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection and NSW Mental Health Ambulatory Data Collection.

The findings from this study will be used to inform local action, service developments and inter-agency service delivery and strategy. The overall aim is to build the capacity of services to better support vulnerable families and children residing on the mid to north coast of NSW.

Reducing the evidence practice gap in preventing rehospitalisation and recurrence following stroke, Professor Amanda Thrift, Monash University

Stroke confers significant morbidity, mortality and economic costs. Approximately 50,000 Australians suffer a stroke each year. However, the uptake of proven treatments such as blood pressure lowering agents is poor. There is also limited evidence of the effectiveness of the Chronic Disease Management (CDM) plans, which are aimed at providing better care in the management of risk factors in those with a chronic disease such as stroke.

The aims of this data linkage study are to (i) describe the uptake of CDM plans and evaluate their effectiveness, (ii) evaluate the effectiveness of guideline-based prescribed secondary prevention medications that are recommended in guidelines for stroke care, (iii) identify any variations in uptake, use and effectiveness of CDM plans and prescribed secondary prevention medications between urban and rural regions, and (iv) evaluate the cost-effectiveness of CDM plans compared to other models of GP care. These endpoints will be assessed based on health outcomes at 1, 2 and 5 years after the stroke event.

The cohort for this study comprises of all patients presenting to the Emergency Department and admitted to hospital with stroke in NSW (and Victoria) over the period 2006-2012. Data will be extracted from Victoria and NSW's hospital and emergency department data sets and submitted to AIHW for linkage with

identified patient records in the National Death Index, Medicare Enrolment File, Medicare Benefit Scheme and Pharmaceutical Benefits Scheme. For NSW, the CheReL extracted data from the NSW Admitted Patient Data Collection, the NSW Emergency Department Data Collection.

Besides providing valuable evidence on the effectiveness of CDM plans for the management of stroke, the data linkage project will also demonstrate a pathway to achieve reliable cross-jurisdictional data linkage between two states' (Victoria and New South Wales) and national AIHW databases and contribute new knowledge in this field.

Health outcomes and service utilisation in a cohort of people who inject drugs, sex workers and 'at risk' young people - a record linkage study, Dr Bradley Mathers, The Kirby Institute, University of New South Wales

People who inject drugs, sex workers and young people engaged in street-based lifestyles ('at risk' young people) represent three overlapping groups who experience poorer health outcomes and a disproportionate burden of disease compared to the general population.

The aim of this project is to identify demographic, behavioural, and clinical factors that predict health and social outcomes in this socially marginalised urban population with high prevalence of injecting drug use and sex work. The study will also determine patterns and predictors of health service utilisation and identify predictors of uptake and outcomes of treatment including opioid substitution therapy and treatment for HIV and viral hepatitis.

This project examines a cohort of clients attending a Medically Supervised Injecting Centre (MSIC) in inner city and those attending a primary health care service very close to the injecting centre. CHeReL linked the cohort to data from NSW Admitted Patient Data Collection and ACT Admitted Patient Collection, NSW Emergency Department Data Collection and ACT Emergency Department Information System, NSW and ACT Cancer Registry, NSW Mental Health Ambulatory Data Collection, Pharmaceutical Drugs of Addiction System NSW, NSW Notifiable Conditions Information Management System and ACT Notifiable Diseases Management System, NSW and ACT Perinatal Data Collection, National HIV Database (NSW Component), National AIDS Registry (NSW Component), NSW Bureau of Crime Statistics and Research Reoffending Database, NSW Offender Management Information System (OIMS), NSW and ACT RBDM Death Registrations, NSW Cause of Death Unit Record File and ACT coded cause of death.

The study is expected to provide a better understanding of the complex health and service needs of these groups towards improving the health of members of these vulnerable populations and reducing the associated burden of disease.

ADjunctive coRticosteroid trEatment iN criticAlly ilL patients with septic shock Health Economic & Outcome Research (ADRENAL Study), Dr Colman Taylor, The George Institute

In NSW, the estimated average cost per day in the intensive care unit is more than $4000 AUD. The costs of treating patients with sepsis and septic shock are thought to be considerably higher than the costs for treating patients without sepsis, in both intensive care and in the hospital ward due to prolonged stay.

The ADRENAL study is an NH&MRC funded randomised, blinded, placebo-controlled clinical trial assessing the effect of corticosteroids in treating patients with septic shock. The primary outcome of is all-cause mortality at 90 days after randomisation. ADRENAL is recruiting from 69 intensive care units (ICUs) across Australia, New Zealand, Denmark, Saudi Arabia and the United Kingdom.

The ADRENAL-CEA project is a national data-linkage based cost-effective analysis to determine the short- and long-term cost-effectiveness, economic and clinical outcomes of using hydrocortisone compared to placebo for treatment of critically ill patients with septic shock. The cohort includes all consented patients randomised to ADRENAL in jurisdictions where data registries are available to obtain resource use costing data. The ADRENAL study database includes information pertaining to the hospital admission including ICU resource use. The project included record linkage of the Adrenal study cohort to admitted hospital data and emergency data across multiple jurisdiction and national mortality data from the AIHW. For NSW data, CHeReL linked the cohort to the NSW Admitted Patient Data Collection and NSW Emergency Department Data Collection and the NSW RBDM death registrations.

The ADRENAL-CEA project provides an opportunity to look beyond the traditional 90-day mortality window and to consider the broader societal and economic implications of surviving septic shock.

Tracking the progression, outcomes and service use of people with hospital and community acquired pressure injury in NSW Australia. Professor Kim Usher, The University of New England

In hospital and community settings, Pressure Injury (PI) also commonly known as pressureulcers or pressure sores, are a leading cause of preventable patient harm and an important patient safety issue. PIs are adverse events associated

with health care that can cause significant patient harm and discomfort, and have been identified as a cause of death. While there are point prevalence studies available, there is no current literature on the state-wide prevalence of PI or the economic burden of PI on the NSW health system.

This retrospective audit study aims to estimate the annual prevalence of hospital- and community-acquired PI in NSW from 2010 to 2015, and to analyse the progression of injury stages, surgery, and/or mortality and to quantify the health-related costs for patients with a hospital- or community-acquired PI.

The study cohort includes admissions for adult individuals with diagnosis codes relevant to PIs from the NSW Admitted Patients Dataset Collection. APDC data will be analysed to estimate the annual prevalence of NSW hospital acquired PIs. Survival analyses and differences in survival among participant sub-groups will be conducted using linked NSW RBDM death data and NSW COD-URF (cause of death) records. Predictors of hospital-acquired PI progression and mortality will be identified. Similar analyses among community dwelling adults in NSW and variances between rural, regional and metropolitan areas and nursing home admission are also included in this study.

PI prevention is an important aspect of health care to prevent the discomfort and morbidity associated with these injuries, as well as reducing health care costs. This important audit will provide more comprehensive and updated picture on the prevalence of hospital and community acquired pressure injury (PI) in NSW and progression, healing or mortality using population based data.

REDUcing the burden of dialysis Catheter ComplicaTIOns: a National approach (The REDUCCTION partnership project) Associate Professor Martin Gallagher, The George Institute for Global Health

Healthcare Associated Infections (HAI) threaten the safety of patients, cause significant and life threatening harm to patients, and bring major additional costs to already stretched health budgets. Patients with kidney disease are especially susceptible to HAI, due to the wide use of central venous haemodialysis catheters. These catheters, while essential to the delivery of the life sustaining dialysis treatment, are a major driver of blood stream infection and contribute to the increased mortality seen in dialysis patients.

The aims of the REDUCCTION data linkage project are to estimate the costs to the health systems associated with dialysis catheter exposure, estimate excess costs (using markers of health service use such as hospitalisation, inter hospital transfers, length of hospital stay) that arise from dialysis catheter infections,

study the association between clinical outcomes such as in-hospital and long-term mortality and dialysis catheter exposure and infection.

The REDUCCTION partnership project involves renal units across Australia. All patients receiving incident vascular access catheters for dialysis within the participating renal units during the study period defined the cohort. For the NSW & ACT components, standardised cohort data was linked to the NSW and ACT Admitted Patient Data Collections, NSW RBDM and the ACT Mortality data collection and the Australia and New Zealand Dialysis and Transplant Registry.

The findings of this study will further medical knowledge and may improve how renal physicians care for kidney disease patients requiring catheters in the future.

Back to top

Examining utilisation of cardiac devices in New South Wales: a data linkage project A/Prof Jodie Ingles, University of Sydney

Automatic implantable cardioverter defibrillators (AICDs) and transcatheter aortic valve insertions (TAVI) are two cardiac procedures that involve surgically inserting a cardiac device to prevent heart failure and/or sudden death. However, there is anecdotal evidence suggesting these devices may be overused in specific patient populations that receive limited clinical benefit from the therapy.

The aims of this retrospective study include characterising the AICD/TAVI population, reporting procedure trends over observation period and examining the association between patient sociodemographic, patterns of care and patient outcomes. This project will utilise population-level, routinely collected data to examine real world patterns of care and patient outcomes in persons receiving AICD or SAVR (standard aortic valve replacement) or TAVI implantation therapy in New South Wales.

For this project persons with an AICD or TAVI procedure code recorded in New South Wales (NSW) hospitalisation data from 2001 to 2017 were linked with NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection and where relevant, NSW Mortality Data (New South Wales Registry of Births, Death and Marriages [NSW RBDM]; Cause of Death Unit Record File [COD URF]) mortality records. The AICD cohort was also linked with NSW Perinatal Data Collection records.

Evidence generated through this project is expected to assist clinicians in determining whether these therapies are suitable for their patients.

Back to top

The Sydney Triage to Admission Risk Tool - 2 (START2): refining a disposition decision support tool to improve patient flow in Emergency Departments. Associate Professor Michael Dinh, Royal Prince Alfred Hospital, NSW

Emergency Departments (ED) in NSW and Australia continue to face enormous challenges with respect to increasing population demand for health care, endemic overcrowding and access block. Novel solutions that are clinician focused and data driven are required to sustainably improve senior clinical decision making in ED, and these have not been described previously in the scientific literature.

This data Linkage project intends to identify risk factors for in-patient admission, define the most appropriate admitting clinical service, as well as flag patients who might receive more appropriate care in an outpatient setting or short stay medical unit.

The Sydney Triage to Admission Risk Tool - 2 (START2) project will refine will previously derived and internally validated a risk prediction tool for ED disposition called the Sydney Triage Admission Risk Tool (START). Data linkage between Emergency Department Data Collection (EDDC), Admitted Patient Data Collection (APDC), and Deaths Registry (NSW RBDM) to outcomes such as length of stay, re-admissions and medical diagnosis in ICD codes is expected to enhance the predictive capabilities of this clinical decision support tool to further streamline the patient's journey.

Back to top

Quality of Care in the Management of Cancer Associate Professor Shalini Vinod, Liverpool Cancer Therapy Centre

There are little data in the Australian population on receipt of best practice care and clinical outcomes. This data linkage study is the first and largest population based study in Australia assessing the use of quality of care indicators and adherence to Clinical Practice Guidelines (CPG) in cancer management.

The data linkage project aims to investigate variations in cancer care by modality (surgery, radiotherapy, chemotherapy, palliative care) and cancer type, identify patient populations where there is a disparity, evaluate patient, tumour and health services factors and the correlation between receipt of quality of care and CPG adherence with clinical outcomes.

A retrospective cohort of breast, prostate, lung, colorectal, cervix or uterine cancer patients diagnosed since 2005 were linked by the CHeReL to the NSW Cancer Registry (NSW CCR), NSW Clinical Cancer Registry data (ClinCR), the NSW Admitted Patient Data Collection (APDC), NSW Registry of Birth Deaths and Marriages (RBDM) death registrations, and Cause of Death Unit Record File(COD-URF). The Australian Institute of Health and Welfare (AIHW) will link the cohort to MBS and PBS datasets.

Multiple comparisons of the quality of care indicators based on clinical evidence and major consensus guidelines or evidence summaries and some specific comparisons depending on the site of cancer are expected from this research. Findings are expected to provide a better understanding on the use of Quality of care indicators and translation of Clinical Practice Guidelines in cancer management in NSW.

Back to top

The evaluation of the impact of a world first state-wide program in reducing cardiac arrests and other adverse events in Emergency Departments in New South Wales Associate professor Jack Chen, The Ingham Institute, University of New South Wales

In order to prevent unexpected cardiac arrests and unexpected deaths in hospitals, the NSW government has taken a state-wide proactive approach by developing standardised policies and guidelines around the deteriorating patient and mandating that every NSW state public hospital implement a rapid response system or RRS (namely, the Between the Flags (BTF) program, Clinical Excellence Commission (CEC) NSW Health, 2008).

The data linkage project aims to examine the effectiveness of the implementation of a two-tiered RRS across every NSW Emergency Department; and to understand the incremental value of the current two-tier RRS system versus the one-tier Medical Emergency team (MET) system in the ED setting.

Adult public hospital patients from four population administrative databases (NSW Emergency Department Data Collection (EDDS) database; NSW Admitted Patients Data Collection (APDC) database; the New South Wales part of the Australia and New Zealand Intensive Care Society (ANZICS) database managed by the Centre of Outcome Research(CORE); and the NSW Registry of Births, Deaths and Marriages (RBDM) from 1 Jan 2005 onwards to June 2017 were linked by the CHeReL, in order to assess if the hospital-wide RRS system across all NSW hospitals reduced unexpected cardiac arrests in the ED and hospital mortality and improved other patient safety indicators.

The Study will analyse these primary and secondary outcomes and their changes before, during and after implementation of the program.

Back to top

Towards Optimising Hospitalised Older Adults Medications Professor Sarah Hilmer, Royal North Shore Hospital

Medicines use in older people is a complex balance between managing disease and avoiding medication-related problems. The prevalence of polypharmacy (concurrent use of five or more different medicines) is increasing, especially in people approaching the end-of-life and living with dementia. Polypharmacy increases the risk of medication errors, adverse drug reactions, falls, confusion, hospitalisation and death. One in five medicines taken by older people is harmful or unnecessary (inappropriate).

This data linkage project aims to define the prevalence and management of inappropriate polypharmacy and their clinical variation in hospitalised older patients (with and without dementia). An electronic decision support system prototype to support deprescribing practices will be developed and piloted followed by an evaluation for feasibility for use across all NSW public hospitals. Further, an economic analyses will be conducted to estimate the potential clinical and economic impact of the intervention to reduce inappropriate polypharmacy in older patients

This retrospective multi-centre cohort study consists of 2000 participants aged ≥75 years and admitted to six hospitals in New South Wales admitted under general medicine, geriatric medicine and rehabilitation. Longitudinal data on the cohorts' clinical outcomes and medication use were obtained through data linkage via the CHeReL. Linked datasets included the NSW Admitted Patient Data Collection (NSW APDC), the NSW Emergency Department Data Collection (NSW EDDC), Registry of Births, Deaths and Marriages (RBDM) and the Australian Coordinating Registry Cause of Death Unit Record (COD-URF). Additionally data from the Pharmaceutical Benefits Scheme (PBS) and the Repatriation Pharmaceutical Benefits Scheme (RPBS) were linked by the Australian Institute of Health and Welfare.

The overall aim of this research is to identify and prioritise inappropriate polypharmacy and inform the process of implementing deprescribing interventions in the hospital setting.

Back to top

Accuracy of multi-parameter first trimester screening in the identification of pre-eclampsia and fetal growth restriction in an Australian population. Associate Professor Andrew Mclennan, University of Sydney

Pre-eclampsia (PE) is a multisystem disorder that affects 2-5% of all pregnant women and is the leading cause of maternal and fetal morbidity and mortality. Relying on obstetric, medical and family history to identify women at high risk of developing PE only identifies approximately 30-40% of cases and has a high false positive rate. After identification, an effective intervention to reduce the prevalence of the disease remains a challenge.

The proposed data linkage study aims to validate first trimester multi-parameter screening test for the identification of pre-eclampsia in a large mixed-risk Australian obstetric population and, provide contemporary assessment of pre-eclampsia incidence. The study will also evaluate the use of a multi-parameter risk algorithm for the prediction of pre-term fetal growth restriction (FGR).

This retrospective cohort comprises of singleton pregnancies between 10 and 14 weeks gestation in women referred to a specialist prenatal screening and diagnostic ultrasound practice in metropolitan Sydney to undertake first trimester screening for adverse pregnancy outcome. For the data linkage project, the CHeReL linked cohort data (i.e. the first trimester screening database, from two sources- Sydney Ultrasound For Women (SUFW) and Royal Prince Alfred Hospital (for women screened in the first trimester at RPAH but not delivered at RPAH)) with matching mothers' and babies' records in the NSW Perinatal Data Collection.

The findings from this study are expected to provide important pregnancy and birth outcome information from the largest population of pregnant Australian women undertaking first trimester screening for pre-eclampsia. This will include valuable contemporary information regarding the true incidence of PE and gestational hypertension in Australia, the accuracy of first trimester screening for PE and the downstream benefits in terms of both health outcomes and costs from appropriately targeted interventions in a population identified at high PE risk.

Back to top

Advance Care Planning for Patients with advanced illnesses attending hospital outpatient clinics: Data linkage Professor Andrew Hayen, University of Technology, Sydney

Advance Care Planning (ACP) is a process of reflection, discussion and communication that enables a person to plan for their future medical treatment and other care, for a time when they are not competent to make or communicate decisions for themselves. ACP could significantly improve the quality of care provided to patients with advanced illnesses by allowing patients to receive patient-centred care and avoid unwanted or inappropriate hospital admissions and treatment.

The data linkage project is part of a larger study and randomised trial looking to see whether a facilitated ACP intervention provided to patients with advanced illnesses having supportive and palliative care needs and attending a hospital outpatient clinic can reduce unplanned hospital admissions at six months, improve patient care and encourage health professionals to incorporate ACP into routine care.

The Centre for Health Record Linkage (CHeReL) performed data linkage between the ACP project dataset and NSW Ministry of Health data from the NSW Ambulance dataset (NSW Amb), NSW Emergency Department Data Collection (EDDC), NSW Admitted Patient Dataset Collection (APDC) and NSW Registry of Births, Deaths and Marriages (RBDM) and the Australian Coordinating Registry Cause of Death Unit Record (COD-URF). The Linked data will be used to compare the intervention and control groups to measure key outcomes; unplanned hospital admissions, acute health services utilisation and health outcomes and to carry out a health economics evaluation.

The project findings will help determine if having facilitated ACP discussions influences patient outcomes or reduces acute health resources utilisation, to inform future practices and hopefully encourage health professionals to partake in ACP discussions.

Back to top

Using linked data to evaluate and improve hip fracture care Dr Lara Harvey, Neuroscience Research Australia

Hip fracture (HF) is the most serious and costly fall-related injury suffered by older people. Delivery of evidence based care for HF can reduce morbidity and mortality, improve function and optimise discharge destination and from a health service perspective, can reduce length of stay, complications and readmission rates.

Australia has an established Guideline for Hip Fracture Care, a Clinical Care Standard with Quality Indicators and the Australian and New Zealand Hip Fracture Registry (ANZHFR). The ANZHFR collects variables that are acute-care focused and provides hospitals with real-time data on performance against a number of quality indicators. The registry, however, does not collect data beyond

the acute episode and cannot assist with understanding the long term impact and ongoing cost of HF.

This data linkage study aims to measure longer-term outcomes for HF patients at various health service levels, explore clinical variation in selected processes and short term outcome measures for HF patients.

Demographic and clinical information were extracted for all individuals aged >=50 years admitted to a NSW hospital with a fall related HF from 1 January 2010 from the NSW Admitted Patient Data Collection (APDC) and linked to the Registry of Births, Deaths and Marriage (RBDM), District and Network Return dataset (NDR), Sub-Acute Non-Acute Patient data (SNAP) and ANZHFR by the Centre for Health Record Linkage (CHeReL). The AIHW undertook further linkage to Commonwealth data from National Death Index (NDI), National Aged Care Data Clearing House (NACDC), the Pharmaceutical Benefit Scheme (PBS) and Australasian Rehabilitation Outcomes Centre Database (AROC).

The project will identify factors (patient/process/ system level) that may contribute to any identified unwarranted clinical variation and provide baseline trend data against which to calculate the clinical and cost-effectiveness of the introduction of the Guideline/Standard/Registry combination in NSW.

Back to top

SAFety, Effectiveness of care, and Resource use among Australian Hospitals (SAFER Hospitals) Dr Isuru Ranasinghe, Basil Hetzel Institute and University of Adelaide

In Australia, more than 10 million hospitalisations occur annually for treatment of a range of acute and elective conditions and this care is becoming increasingly expensive. However, very few outcomes of hospital care are measured or reported nationally despite increasing local and global concerns about variation, quality, appropriateness and escalating costs of hospital care.

The SAFety, Effectiveness of Care, and Resource Use among Australian Hospitals (SAFER Hospitals) study is a multidisciplinary research collaboration to evaluate the safety and effectiveness of hospital care, and the impact on cost and resource utilisation in Australian hospitals. The goal of this study is to estimate the hospital-wide incidence of serious adverse events, unplanned readmissions, mortality and costs following hospital care using existing linked data and advanced statistical and machine-learning based computational methods. It seeks to assess the variation in these outcomes among hospitals and estimate the proportion of outcomes that may be preventable.

The SAFER hospitals study is part of a larger national observational cohort study and includes data from multiple Australian jurisdictions. The data linkage for NSW and ACT data was carried out by the CHeReL. Cohort data included hospital admissions from 1 January 2012 from NSW Admitted Patient Data Collection (APDC) and ACT Admitted Patient Collection (APC). This data was linked to the NSW Emergency Department Data Collection (EDDC), and Registry of Births, Deaths and Marriages (NSW RBDM), and the ACT Emergency Department Information System (EDC), Registry of Births, Deaths and Marriages (ACT RBDM).

The SAFER Hospitals study is expected to enhance our understanding of quality and cost of care delivered among Australian hospitals and lead to better methods for routine monitoring of these outcomes. Moreover, it will identify priority targets for quality improvement efforts and will inform the development of cost-effective clinical and policy interventions to improve hospital care and patient outcomes.

Back to top

Preventing adverse events in opioid substitution therapy Dr Sarah Larney, National Drug and Alcohol Research Centre, University of New South Wales

Opioid Substitution Therapy (OST) with drugs such as methadone is an effective treatment for opioid use disorder. However, important questions regarding risk of death and non-fatal adverse clinical outcomes following OST, remain to be answered.

The aim of this research project is to understand the extent of risk of adverse clinical outcomes during OST with methadone and buprenorphine, and identify patient and provider risk factors for these adverse outcomes. Building on this work, the researchers aim to develop a risk prediction model that can identify patients at greatest risk of adverse outcomes using machine learning techniques to explore a wide range of potential predictors.

This retrospective cohort study utilises NSW data from settings where OST is well-established with use of both methadone and buprenorphine across these settings. The participant cohort will include all OST patients in NSW treated from 1 August 2001. Cohort data will be obtained from the Electronic Recording and Reporting of Controlled Drugs (ERRCD; formerly PHDAS) system and linked to NSW Admitted Patient Data Collection (APDC), NSW Emergency Department Data Collection (EDDC), NSW Mental Health Ambulatory Data Collection and NSW Death Registrations/Cause of Death Unit Record File (RBDM and COD-URF). Additionally incarceration data from the Re-offending Database, maintained by the NSW Bureau of Crime Statistics and Research (BOCSAR ROD) will also be linked.

Results from this research will allow for the development of strategies and clinical protocols to ensure that patient safety and quality of care are maintained as OST is scaled up. It will identify models of care with lower incidence of adverse events.

Back to top

Understanding health service system needs for people with intellectual disability Professor Julian Trollor, University of New South wales

People with Intellectual Disability (ID) are a minority group with significant health inequalities which require detailed examination and concerted action. People with ID are at elevated risk of a number of potentially preventable diseases, and have lower life expectancy than other Australians.

Using a cohort of NSW residents, the large scale population based study aims to profile the health status, health resource utilisation, and associated costs for people with ID and compare these with a matched cohort without ID from the NSW population. Frequency and associations for prescribing of medicines in people with ID will be determined and compared to the non-ID group. The researchers will also evaluate the impact of the transition to the National Disability Insurance Scheme on health resource utilisation and determinants for people with ID.

To establish the cohort, CHeReL combined and de-duplicated personally identifying information of people of all ages who met specific requirements as identified from several NSW ID service datasets. This included Disability Services Minimum Data Set (DS-MDS), Admitted Patient Data Collection (APDC), Emergency Department Data Collection (EDDC), Mental Health Ambulatory Data Collection (MH-AMB), Corrective Services NSW Disability Data (SDS), targeted specialist support services in NSW public schools from the NSW Department of Education, NSW Public Guardian Data, and NSW Ombudsman datasets. CHeReL forwarded encrypted identifiers for all datasets potentially linking to the ID/non-ID group to AIHW. AIHW identified the non-ID cohort and linked the ID/non-ID cohort to Commonwealth datasets and CHeReL linked ID/non-ID cohort to NSW datasets.

Overall, the findings from this project are expected to directly influence strategies directed at improving the health of people with ID. This cohort study will create the largest and most comprehensive linked data set relating to the health profile of people with ID.

Back to top

Baseline for monitoring the burden of rheumatic heart disease in Australian jurisdictions: New South Wales component Dr Judith Katzenellenbogen, the University of Western Australia

Rheumatic heart disease (RHD) is a preventable condition which has its origins in a childhood bacterial infection eliciting an auto-immune response called Acute Rheumatic Fever (ARF). This may cause lifelong heart valve problems leading to RHD. RHD rates reported for Australian indigenous people are among the highest in the world.

Using linked hospital, death and infectious diseases notification data, this study aims to establish current burden and distribution of ARF and RHD in NSW, and the impact of ARF and RHD on the Healthcare system. The Project includes similar data and analysis from other jurisdictions which have RHD registers, namely Western Australia, Northern Territory, Queensland and South Australia.

The NSW cohort includes all persons with ARF/RHD notifications in the NSW RHD Register and NSW Notifiable Conditions Information Management System (NCIMS), ARF/RHD hospital admissions in the NSW Admitted Patient Data Collection (APDC) and NSW Emergency Department Data Collection (EDDC), RHD deaths in the NSW RBDM Death Registrations and Cause of Death Unit Record File. The cohort data was extracted by the CHeReL and then linked to clinical and other data from these datasets and cardiac surgery data from the Australia-New Zealand Society of Cardiac and Thoracic Surgeons (ANZSCTS) registry.

From the linked data, the researchers expect to map the incidence of acute rheumatic fever, progression to RHD, prevalence of RHD and factors determining complications such as stroke, atrial fibrillation and premature death within the cohort. Health care costs will also be determined.

These data will feed into the research program of NHMRC-funded RHD Centre for Research Excellence and inform the RHD Endgame Strategy Report. This document will be used by the six peak health bodies of the END RHD Coalition to outline what approaches are needed to reduce the RHD burden among Indigenous Australians to the level among their non-Indigenous counterparts.

Back to top

Understanding the impact of dementia on rehabilitation following hip fracture to improve health outcomes for older people: Stage 1 Associate Professor Rebecca Mitchell, Macquarie University

Hip fracture represents a serious injury for older people ≥65 years, with falls the most common cause of hip fracture. Risk factors for fall-related hip fracture include comorbid conditions, polypharmacy, osteoporosis, poor balance and vision. Dementia, in particular, can increase fall risk due to changes in a person's ability to recognise and negotiate hazards. Older people with dementia are up to six times less likely to be offered in-hospital rehabilitation following a hip fracture, despite evidence that when people with dementia received rehabilitation their functional ability improves.

The project aims to determine temporal trends in hip fracture rates, the impact of dementia on hip fracture and other health outcomes, treatment costs for older people living with a hip fracture; and identify factors influencing access to hospital-based rehabilitation services for older people with hip fracture with or without dementia.

For this retrospective study, the CHeReL extracted cohort data by including all hip fracture hospitalisations (2007-2017) identified in the NSW Admitted Patient Data Collection (APDC) of individuals aged 65 years or older at the time of admission. Comorbidities were identified through linking APDC records from a one-year lookback period. The APDC data was linked to all hospitalisation data from the APDC, mortality data from the NSW Registry of Births, Deaths and Marriages (RBDM Death Registrations) and NSW Cause of Death Unit Record File (COD-URF) and rehabilitation data from the Subacute and Non-Acute Patients database (SNAP) post hip fracture admission.

The overall research objective is to create a snapshot of hip fracture and health outcomes for older people living with or without dementia.

Back to top

Epidemiology of respiratory failure: Outcomes of hypercapnic respiratory failure among adults in Liverpool, Australia. Dr Hima Vedam, Liverpool Hospital and University of New South Wales

Respiratory failure occurs when the respiratory system is unable to perform its primary function, that is, to move air in and out of the lungs. Hypercapnic respiratory failure (HRF) is a subset of respiratory failure characterised by high arterial carbon dioxide levels. In many people, HRF can lead to hospital admissions and premature death.

There is very little information on the outcomes of people who develop HRF. This is partly because HRF does not reflect a single condition, but can arise from any of a combination of disease, drugs and injury to respiratory system components. However, it is increasingly recognised that the co-existence of multiple health conditions confers additional risk for adverse health outcomes.

The main aims of this study are to understand clinical outcomes (hospital admissions and mortality) for adults with HRF, investigate the influence of comorbidities and socio-demographic factors on health outcomes and the overall burden of disease.

The cohort for this study was selected by the investigators by reviewing medical records among patients attending Liverpool hospital during the study period who satisfied a number of clinical parameters including presence of HRF. The CHeReL linked the cohort data to NSW Admitted Patient Data Collection (APDC), NSW Emergency Data Collection (EDDC) and NSW Registry of Births, Deaths and Marriages (RBDM) death registrations, and NSW Cause of Death-Unit Record File (COD-URF).

The linked dataset will be used to determine healthcare usage patterns and survival for a cohort of people identified as having HRF. This is the first study of its kind and will set the groundwork for future studies on interventions to reduce associated morbidity and mortality.

Back to top

Coronary heart disease in men and women aged under 55 years: developing an evidence base for improving prevention and management Dr Lee Nedkoff, the University of Western Australia

There is increasing evidence that the burden of coronary heart disease (CHD) is worsening in people aged under 55 years in Australia. Recent data showed increasing incidence of acute presentations of CHD including heart attacks in this age group. Rigorous studies using single-state data are difficult because of the relatively smaller number of events in this younger age group compared with older people.

This retrospective cohort study utilises multi-state linked data from WA, NSW and SA and clinical registry data to provide reliable measures of rates of CHD, particularly heart attacks, in people aged under 55 years.

For NSW, the cohort was identified as all patients >= 20 years with any of the CHD related diagnosis/procedure codes in the NSW Admitted Patient Data Collection (APDC), or death from CHD in the NSW Cause of Death-Unit Record File (COD-URF). The CHeReL then extracted all linked records from the NSW Admitted Patient Data Collection (APDC), NSW Emergency Data Collection (EDDC) and NSW RBDM deaths, and NSW Cause of Death-Unit Record File. The linked data will be used for research to provide aggregated measures of hospitalisation, incidence and recurrence rates over time, and comparison of recurrence risk and mortality outcomes. The focus will be on comparisons by age

group (< 55 year olds vs older age groups), and comparisons within the <55 year age group (men vs women).

The project will enable advanced investigation of the burden of CHD in people aged under 55 years in Australia, investigate contemporary trends in ACS and CHD incidence, recurrence, survival, clinical profile and risk factors, in people aged under 55 years and estimate the cardiovascular risk factors which contribute the highest population risk to younger people with CHD in Australia.

Back to top

Evidence for suicide prevention in planning transitions from employment to retirement in older age populations Professor Andrew Page, Western Sydney University

Suicide remains a significant public health problem in Australia, and an emerging problem in older age cohorts. There is evidence to suggest that changes in employment and transition to retirement may increase the likelihood of suicidal behaviours. Understanding the impact of transitions from employment to retirement will provide evidence to inform suicide prevention initiatives in this age-group.

This project aims to investigate the association between the transition from employment to retirement on the risk of suicide and attempted suicide in older age Australians. Other aims include investigating the impact of socio-economic resources, mental health service use and other social supports on the risk of suicide and attempted suicide in those who retire involuntarily compared to those who remain employed or who retire voluntarily.

This project utilises a prospective cohort study design. All participants recruited into the NSW 45 and Up Study at baseline with incident cases of suicide and attempted suicide enumerated over a 10-year follow-up period (2006-2015) were linked to administrative databases from NSW and ACT via the CHeReL: The Admitted Patient Data Collection (APDC), Emergency Department Data Collection (EDDC), Mental Health Ambulatory Data Collection (NSW only) and the Registry of Birth Deaths and Marriages and the Australian Bureau of (Statistics) Cause of Death Unit Record File.

Observational evidence generated from this research is expected to facilitate suicide prevention initiatives and quality improvement in mental health, social and employment services in older age cohorts, mental health referral pathways and processes, and broader social policy recommendations for the period of transition from employment to retirement in older age Australians.

Back to top

Sex disparities in management of myocardial infarction and other cardiovascular diseases Professor Mark Woodward, The George Institute, The UNSW and University of Oxford

Cardiovascular disease (CVD) is the leading cause of death amongst Australian women. Coronary heart disease (CHD), including Myocardial Infarction (MI), is the major component of CVD. MI accounts for around 11,000 female deaths in Australia each year. Several international studies have found sex differences in the control of cardiovascular risk factors among those with established CHD and in the prescription of evidence-based medications that may be responsible for women's lower likelihood of achieving treatment targets.

The aim of this study is to identify and quantify sex disparities in care and outcomes for MI or other CVDs, and explore how these vary across key population subgroups including age, social class and Indigenous status. This study will benchmark current treatments against Australian recommended standards for the secondary prevention of CVD, determine the risks of adverse outcomes and analyse the patterns of sex differences.

To achieve this, the researchers aim to carry out a retrospective population-based cohort study using linked administrative and survey data of ~100,000 women and men admitted to hospital with incident MI and other CVD. This includes any of the multiple diagnosis or procedure codes (related to MI or CVD) within a record from the NSW hospitalisation, emergency, ambulance or mortality administrative datasets.

The cohort data was extracted by the CHeReL and linked to NSW Admitted Patient Data Collection (APDC), NSW Emergency Department Data Collection (EDDC), NSW Ambulance, NSW Registry of Births, Death and Marriages (RBDM), NSW Cause of Death Unit Record File (COD-URF), NSW Perinatal Data Collection (PDC) and the largest cohort study of older Australians-45 & Up Study and Cardiothoraic Physiotherapy Database (CuPID). Additionally, the CHeReL provided the identifiers to AIHW for linkage to Pharmaceutical Benefits Scheme (PBS), Medicare Benefits Schedule (MBS), and National Death Index (NDI).

The study is expected to inform appropriate sex-specific coronary care pathways, which are urgently needed to achieve the enormous potential to improve the cardiovascular risk profile of Australian women and men.

Back to top

Understanding serious injury and burn patient transfer processes, patient experiences and models of care for Aboriginal and Torres Strait Islander children in Emergency Departments in New South Wales Dr Kate Hunter, The George Institute for Global Health

Aboriginal and Torres Strait Islander children are over-represented in serious injury compared with other Australian children. Falls, road-related injuries and burns are some of the leading causes of injury.

This observational study aims to describe serious injury presentations of children to trauma centres in NSW by Aboriginal and/or Torres Strait Islander status, by injury type and severity, by age, geographic area and available socioeconomic variables. The research will also describe and examine differences in hospital care received by Aboriginal and/or Torres Strait Islander children compared to that received by non-Aboriginal children.

All children on the NSW Trauma Registry aged up to 16 years over the study period who were admitted to a NSW trauma service within a week of either sustaining a serious injury or admitted to an Intensive Care Unit following injury or died in hospital following injury were included in the study cohort.

For this linkage project, the CHeReL linked cohort data from the NSW Trauma Registry with the NSW Emergency Department Data Collection (EDDC), the NSW Admitted Patient Data Collection (APDC) and NSW Birth Registrations (RBDM Births) to enable the research team to examine the NSW Trauma Registry data by Aboriginal and Torres Strait Islander status. Linked data was used to describe the number of Aboriginal and/or Torres Strait Islander children who are treated for serious injury in NSW trauma centres NSW, examine differences in injury presentations and examine whether their care pathways or outcomes differ in any way from those of non-Aboriginal children

In combination with other work, findings from this study will be used to inform the development of updated, relevant referral guidelines and models of trauma care for emergency departments.

Back to top

Evaluating highly sensitive troponin in Emergency Departments. The TropED study. Associate Professor Thomas Briffa, University of Western Australia

Troponin (Tn) tests are a sensitive method of detecting heart muscle damage and the introduction of these tests have changed how patients with chest pain and suspected acute coronary syndrome (ACS) (i.e. suspected myocardial infarction or MI) are investigated in the Emergency Department (ED). Recently developed, next generation highly-sensitive Troponin (hsTn) tests promise to offer better diagnostic capability in the ED enabling earlier and more sensitive diagnosis of a MI. However, the impact of this test upon clinical practice, model of care, patient outcome, hospital efficiency and health budgets is unknown.

The aim of this study is to compare one year outcomes and costs in those tested with non-hsTn versus those with hsTn and determine if any improvements in efficiency have occurred in EDs due to the introduction of this new technology. This pre-post stratified study will use linked data to evaluate treatment, management, cost and outcome at 1 year before and after these new blood tests were introduced in a national multi-hospital study

The study cohort consists of consecutive persons presenting to EDs with suspected MI and a Tn test ordered from multiple Australian sites. Cases for both pre- and post-cohorts will be identified from the ACT Pathology database for Canberra and Calvary Hospitals. The CHeReL linked cohort data to matching records from the ACT Emergency Department Data Collection, ACT Admitted Patient Care and ACT Mortality Data Collections.

This study is expected to provide a population-based evaluation on how these new and expensive hsTn tests are being used and whether they result in improved care, outcomes and system efficiencies for a life-threating condition.

Back to top

The implementation of an evidence-based treatment in the hospital-to-community pathways for children & adolescents with anorexia nervosa. Dr Sarah Maguire, University of Sydney and Sydney Local Health District

Anorexia nervosa (AN) is a severe mental health illness, characterised by extreme food restriction that affects every bodily system and is life threatening. The NSW Government funded ‘NSW Health Service Plan for Eating Disorders 2013-2018’ to improve access to treatment, to overhaul service delivery, and to support innovation and improvement in care for people with eating disorders.

The researchers of this study undertook the program which is responsible for the development of evidence-based pathways to care for people with eating disorders. For Children and Adolescents, the Maudsley Family Based Treatment or MFBT is a clear evidence-based treatment supported by multiple large and multi-centre randomised controlled trials. However, currently in NSW, there is

variability across hospital and community care in relation to implementation of this pathway.

The data linkage study aims to examine variations in the delivery of evidence-based treatment in the hospital and community pathways for children & adolescents with AN in NSW local health districts (LHDs.

The cohort for this study included all children and adolescents (<18 years) who presented to an emergency department and were admitted to a NSW public or private hospital, or registered as a client with a CAMHS team with either a primary or secondary diagnosis of anorexia nervosa. The primary data was obtained by collating information obtained via file audits conducted at community child and adolescent mental health services (CAMHS) that had a child or adolescent registered in the identified sample. The CHeReL linked the cohort data to the NSW Admitted Patient Data Collection (APDC), NSW Emergency Department Data Collection (EDDC), NSW Mental Health Ambulatory Data Collection and the NSW Mental Health Outcomes and Assessment Tools Collection (MHOAT).

The research is expected to provide valuable information on the extent of implementation of this evidence-based pathway over a three-year period 2017-2019, identify relevant enablers and barriers to its implementation and establish a set of performance indicators to guide improvement.

Back to top

A study of the NSW Mental Health Review Tribunal: Characteristics and Outcomes of Forensic Patients Associate Professor Kimberlie Dean, The University of New South Wales

Mental disorders, particularly severe mental disorders, are known to be associated with an elevated risk of violent and other offending behaviour. Mentally disordered offenders are diverted from the criminal justice system to mental health services on the basis that such individuals require treatment rather than punishment. There is also an expectation that such diversion for treatment will reduce the risk of reoffending. The evidence for the latter is, however, not well established.

This longitudinal retrospective cohort study will establish the longitudinal health contact and outcome profiles of mentally disordered offenders (termed Forensic Patients in NSW) who have come under the jurisdiction of the NSW Mental Health Review Tribunal (MHRT): those who have been found unfit to be tried for an offence, and those who have been found not guilty by reason of mental illness (NGMI). Additionally, the researchers will use Forensic Patient Database (which has the NSW MHRT and BOCSAR Reoffending Data) to examine their socio-

demographic, clinical and forensic characteristics and changes over time, the rate of reoffending once released from secure care, and duration and predictors of detention for these Forensic Patients.

The CHeReL facilitated this study by linking the cohort data from the Forensic Patient Database to statewide health datasets including the NSW Admitted Patient Data Collections (APDC), NSW Emergency Department Dataset Collection (EDDC), NSW Mental Health Ambulatory dataset, NSW Death Registrations (RBDM) and Cause Of Death Unit Record File (COD-URF).

This project aims to fill a significant gap in the literature on mentally disordered offenders by examining their needs, characteristics, and long-term health and criminal pathways. In doing so, the project will provide insight into the specific needs and characteristics of Forensic Patients in NSW, and also allow for an assessment of the efficacy of the NSW MHRT's diversion program.

Back to top

Evaluation of the Early Psychosis Youth Services (EPYS) program: ecological analysis of health service utilisation Associate Professor Laurent Billot, The George Institute of Global Health

Psychotic disorders are among the most burdensome and costly illnesses worldwide. The Early Psychosis Youth Services EPYS program delivered through the National Youth Mental Health Foundation provides early intervention mental health services to 12-25 year olds. The program aims to reduce the incidence and severity of psychosis within the community through prevention, early detection and coordinated care delivery.

The overall purpose of the evaluation project is to determine the impact of the program and inform future policy direction. The data linkage sub-study focuses on measuring the effectiveness and cost-effectiveness of the program by analysing health service utilisation and quality of life.

The cohort for this study included all persons born between Jul 1990 and Jul 2005 with a hospitalisation record with a diagnosis code for pyschosis after Jul 2010. Cohort data was linked by the CHeReL to the data from the NSW Admitted Patient Data Collection (APDC), NSW Emergency Department Data Collection (EDDC), NSW Registry of Births, Deaths and Marriages (RBDM), NSW Mental Health Ambulatory (MH-AMB) Data Collection and the Mental Health Outcomes and Assessment Tools (MH-OAT) Data Collection.

The linked data will be used to analyse rates of hospital admissions and emergency department (ED) presentations to assess temporal changes in health service utilisation in young people with early psychosis and compare temporal

changes between geographical areas that include EPYS and those that either include non-EPYS state services or no specific services.

Back to top

Impact of medical and mental health comorbidities on hospital outcomes and trends in major trauma patients: a state-wide data-linkage study from New South Wales, Australia Michael Dinh, NSW Institute of Trauma and Injury Management

Trauma and injury are among the leading causes of morbidity and mortality around the world. A considerable proportion of trauma patients have comorbidities at the time of admission. Both medical and mental health comorbidities can complicate recovery from severe injury, increase the likelihood of complications in hospital and lead to poorer outcomes after discharge in the community. The role that pre-existing medical or mental health conditions on hospital outcomes such as re-admissions to hospital and resource utilisation remain poorly understood and it is not yet evidenced which types of comorbidities are likely to influence hospital outcomes.

The objectives of this project are to describe trends in medical and mental health comorbidities over five years (2012-2016) and to determine the association between comorbidities and hospital outcomes following severe injury. The CHeReL facilitated this study by linking a cohort of patients identified from the NSW State-wide Major Trauma dataset to NSW Admitted Patient Data Collection and NSW RBDM deaths.

The study is anticipated to contribute to improving outcomes data for complex trauma patients across NSW and to for providing better models of care for hospitalised trauma patients with medical or mental health comorbidities across NSW.

Back to top

Australian inherited heart disease data linkage study Dr Jodie Ingles, Centenary Institute

Inherited heart diseases (IHDs) are relatively rare medical conditions which affect 1 in 200 people. Consequently, there is limited insight into the routine patterns of care for these patients, long term treatment outcomes, or the nature of a patient's interactions with the health care system.

This project aims to use the Australian Genetic Heart Disease Registry (AGHDR) to create a large, well-characterised cohort of persons who have a clinically confirmed diagnosis of an IHD or have been identified as a silent gene carrier

associated with an IHD as a means to describe the cohort, examine real world patterns of care and determine the agreement between data sources (AGHDR and State-based data collections). The CHeReL facilitated this study by linking data from AGHDR to NSW Admitted Patient Data Collection, NSW RBDM Death Registrations, Cause of Death Unit Record File and NSW Emergency Department Data Collection.

This project provides an opportunity to gain a broader and more in depth understanding of the overall medical burden of being diagnosed with an inherited heart condition. These findings have the potential to influence treatment guidelines and patterns of care for persons with an inherited heart disease both within Australia and globally.

Back to top

Positive life pathways for vulnerable adolescents: The role of a life management program Dr Sally Nathan, University of New South Wales

Young people in contact with the criminal justice system who have problematic use of drugs and alcohol often lack opportunities for social and economic participation in society and many continue offending into adulthood.

This project examines the short and longer term outcomes and pathways of such young people who participate in a Program for Adolescent Life Management (PALM) compared with similar young people who have not completed such a program. PALM collects data (including key variables such as criminal activity, education, social and family functioning, mental health and drug and alcohol use) at referral providing a unique dataset from which a study can examine these young people's pathways into and out of the program.

The CHeReL facilitated this project by linking data from the PALM database to BOCSAR Re-offending Data Collection, ACT Police, NSW Mental Health Ambulatory Data Collection, NSW Admitted Patient Data Collection, ACT Admitted Patients, NSW Emergency Department Data Collection, ACT Emergency Department, NSW Registry of Births Deaths and Marriages deaths, ACT Births Deaths and Marriages deaths, Cause of Death Unit Record File, NSW Notifiable Conditions Information Management System and ACT Notifiable Diseases Management System.

This study will improve understandings of the pathways of these vulnerable young people and the points at which their life trajectories may change, significantly strengthening knowledge about different outcomes and possible ways to intervene effectively.

Back to top

Mapping the overlap between mental health and drug and alcohol service use in New South Wales

Health Services Professor Anthony Shakeshaft, University of NSW

The Global Burden of Disease study (2010) demonstrated that mental health and substance use disorders accounted for over 7% of all disability-adjusted life years (DALYs) worldwide. At present, little is known about individuals who use treatment services for both mental health and substance use disorders. Now, for the first time in NSW as a result of new data reporting requirements, there is capacity to link mental health and drug and alcohol administrative datasets.

The aim of this project will be to identify the characteristics of clients who actively seek treatment from both mental health and drug and alcohol treatment services. This population will be compared to two comparison populations: those who attend mental health services only and those who attend drug and alcohol services only. Data from the following datasets was linked by the CHeReL for this project: the NSW Minimum Dataset for Drug and Alcohol Treatment Services, NSW Mental Health Ambulatory Data Collection, NSW Admitted Patient Data Collection, RBDM death registrations, Cause of Death Unit Record File, and NSW Emergency Department Data Collection.

Expected benefits of this project include improved service planning and targeting of appropriate care which is anticipated to result in reduced duplication of services and reduced costs to community health systems. This in turn can lead to improved wellbeing and social functioning for people living within the community who are affected by mental illness and substance misuse.

Back to top

Extended Donor Vigilance: Data Linkage and Evaluation of Health Outcomes in Older Blood Donors Dr Stephen Wright, Australian Red Cross Blood Service

As the Australian population ages, including Australian Blood donors, there will be an expected increase in ageing associated morbidities. Consequently, the demand for blood and blood products in Australia will rise. Without expanding the current donor pool, reliance on existing donors to meet supply demands can be achieved through increasing the overall frequency of individual blood donation. However the long-term health impacts of frequent blood donation are not well understood.

The overall aim of this project is to facilitate access to large, world-class, health data in order to answer pertinent questions on health outcomes and long-term blood donation careers. The first phase of this project is to conduct a feasibility study, whereby the data-linkage rates (number and quality) between the 45 and Up study the Blood Service can be examined. The CHeReL facilitated this study

by linking the 45 and Up cohort to data from the Australian Red Cross Blood Service, and the NSW Admitted Patient Data Collection.

The expected benefits of this research are to those in the population of people that donate blood regularly. Output from this research will help inform, confirm, and further develop the existing safety-oriented blood donation policies. Importantly this study will contribute high-quality evidence examining regular blood donation and long-term health outcomes in older blood donors.

Back to top

NSW Unplanned Hospital Readmissions Mr Justin Gardiner, NSW Health

In Australia, the rate of unplanned readmission to hospital is around seven percent. Approximately fifteen percent of these unplanned readmissions have been determined to be potentially avoidable. From a national perspective, reducing these unplanned readmissions from 2.2 percent to 0.53 percent had an estimated savings of over $100 million in 2012. While readmission rate can be a good indicator of care, some readmissions are unavoidable, regardless of the quality of care during the index admission and continuity of care in the community. Identifying these unavoidable readmissions (and thus the avoidable readmissions) will potentially allow for increased quality of care.

The aim of this project is to create an operational definition for potentially preventable hospital readmissions (PPHR) based on accessible data; to categorise patient groups (and their care) at high risk of PPHR; to develop analytical methods to support the management of PPHR; and include the development of a model for early and accurate identification of PPHR for individual patients. In Part A of this project the CHeReL linked records from Northern NSW LHD Unplanned Hospital Readmission Audit with NSW Admitted Patient Data Collection and NSW Emergency Department Data Collection. Part B utilises de-identified linked data from the Admitted Patient, Emergency Department and death registration data collections established under Public Health and Disease Registers provisions of the NSW Public Health Act 2010 (previously linked by the CheReL).

Results of this project should enable a standardised definition, making it easier to compare studies, form judgements on data requirements and provide a standardised target for calculating readmission rates. Being able to accurately and automatically categorise patients who have been readmitted will improve planning and healthcare outcomes. Being able to accurately predict a patient's risk of readmission would potentially lower readmission rates and allow for a higher quality of care.

Back to top

A review of deaths occurring during treatment with methadone between 2003-2013 in Victoria and New

South Wales, Australia Dr Jennifer Pilgrim, Monash University

Misuse and accidental overdose of methadone is a growing and widespread problem in Australia that warrants immediate attention. Reducing methadone related deaths requires a combination of research, education, law enforcement and public health initiatives.

This project aims to identify such initiatives and potential risk factors for methadone toxicity through an in-depth study of deaths associated with methadone in Victoria and NSW.

The CHeReL facilitated this project by linking a cohort of all methadone-related deaths in NSW identified through the National Coronial Information System (NCIS) to the Pharmaceutical Drugs of Addiction System (PHDAS) methadone subsystem and the PHDAS non-methadone subsystem, for the identification of methadone prescribing and permit information. This NSW data will be then be compared with a similar cohort from Victoria enabling the examination of trends between states.

The potential benefits of this proposed research are that the publication of aggregated data can help to define the scope of the phenomena, identify risk factors, and assist clinicians and policy makers to improve the safety of methadone treatment and reduce the risk of fatal toxicity in accidental or deliberate overdoses.

Back to top

The effect of prenatal and antenatal factors on outcomes for mothers and babies: The use of detailed maternity data in NSW Professor Hannah Dahlen, Western Sydney University and Associate Professor Charlene Thornton, Flinders University

Over 60% of women who give birth in New South Wales (NSW) are affected by a medical conditions such as obesity, diabetes, depression, anxiety, high blood pressure or substance reliance (smoking and other legal and illegal drugs), either before or during their pregnancy. The short and long term effects of these issues are not well understood.

This study proposes to use the detailed databases maintained by individual maternity units at Westmead, Nepean and Blacktown Hospitals to establish baseline numbers of women affected, to see if the numbers of these conditions have changed over time and to see if women with these conditions have different pregnancy, birth and delivery outcomes. To assist in determining the long term health of these women and their babies, the CHeReL linked data from this cohort to NSW Admitted Patient Data Collection, NSW RBDM Death Registrations and

Cause of Death Unit Record File. The use of these additional datasets will allow the study to examine relationships between pregnancy and birth events and future disease.

The level of detailed evidence proposed in this study will provide unprecedented information for clinicians and administrators in the provision of services to the maternity population in NSW. This will positively affect pregnancy, birth and longer term health outcomes for both mother and babies.

Back to top

Temporal trends in the incidence, site and survival of metastatic breast cancer in Australia Associate Professor Sarah Lord, The University of Notre Dame

There have been major advances in the treatment of early breast cancer and the management of metastatic disease over the last decade with the availability of new more effective adjuvant systemic therapies. However, the impact of recent treatment advances on the natural history of metastatic breast cancer (MBC) at a population level has not been described.

This project aims to compare two cohorts of women with a first breast cancer diagnosis registered in 2001-2002 or 2006-2007. This comparison will test the hypothesis that advances in adjuvant therapies have reduced the 5 year cumulative incidence of metastases in women with an initial diagnosis of non-metastatic disease, with a greater relative risk reduction to some sites, such as bone, compared to liver and brain. The research team will also examine differences in MBC survival by time to, and site of, first metastasis, socioeconomic status and area of residence. For this study, the CHeReL linked data from NSW Central Cancer Registry, NSW Admitted Patient Data Collection, BreastScreen NSW, NSW Registry of Births, Deaths and Marriages. The CHeReL provided the AIHW with personal identifiers for the cohort to enable linkage to the Pharmaceutical and Medicare Benefit Schemes.

This project will bring benefits to future women with a diagnosis of breast cancer and their families as well as to the wider community through a greater scientific understanding of the disease and prognosis. It will also provide information about any inequalities in prognosis for particular subgroups of women such as those living in rural or remote areas that can be used to inform planning of appropriate accessible health services.

Back to top

Advance care planning in incurable cancer patients with disease progression on first line chemotherapy: a randomised trial Professor Martin Tattersall, The University of Sydney

In the last 20 years the end of life (EOL) care of cancer patients has not kept pace with improvements in treatments directed at the cancer. The aggressiveness of cancer care near the end of life has been increasing with patients often choosing cancer treatments of limited benefit and with potential for harmful side-effects based on ignorance or overestimation of their life expectancy.

This project aims to evaluate in a randomised controlled trial the effect of a formal advance care planning intervention (ACP) on the documentation of patient wishes, compliance with known EOL wishes and the quality of death of patients with progressive incurable cancer on first line chemotherapy. The quality of life of patients subsequent to the intervention, the impact of death on surviving family and the costs of care will also be assessed. The CHeReL facilitated this study by linking data from a cohort of patients with incurable cancer recruited to an RCT on first line chemotherapy to NSW Admitted Patient Data Collection (APDC), NSW Emergency Department Data Collection (EDDC) and NSW Registry of Births Deaths and Marriages (RBDM) death registrations.

The ACP intervention, should it prove successful, has the potential to improve the quality of remaining life as well as the quality of death for patients with advanced, incurable cancer in the community. This improvement in the patients' quality of life and death also has the potential to have a positive impact on their carers' quality of life. This intervention has the potential to be widely adopted in cancer care.

Back to top

Trends in Radical Prostatectomy and Brachytherapy for prostate cancer: readmissions and secondary procedures Adjunct Associate Professor David Smith, Cancer Council NSW

Prostate cancer is a major public health issue internationally and the most commonly diagnosed cancer among Australians and is the second most common cause of cancer death in males. Two common treatments for prostate cancer include radical prostatectomy (RP) and brachytherapy. Each comes with benefits and risks of side effects, however, there is little local data with which to document the trends in the post-surgical complications or readmissions after these procedures. A radical prostatectomy can be performed as a perineal or retropubic approach, or with a robot assisted laparoscopic technique. Considerable evidence has documented both similarities and differences in complication rates between these robot assisted and open surgical approaches.

This proposed project will obtain and analyse a cohort of men recorded by the NSW Admitted Patient Data Collection (APDC) who have had either a RP or brachytherapy procedure in NSW. It aims to document the trend in the use of radical prostatectomy and brachytherapy in NSW and determine whether there are differences in the length of hospital stay after open radical prostatectomy

versus robotic assisted laparoscopic radical prostatectomy. The CHeReL linked this cohort of men to other APDC records and NSW RBDM death registration data.

This data will reflect the population-wide patterns of care in NSW and document the complications and readmission rates that arise from them. The significance of this study will result in more current and local data available to men undergoing these procedures as well as the clinicians performing them.

Back to top

The injury comorbidity index study **Dr. Janneke Berecki-Gisolf, Monash University Accident Research Centre and Ms. Tharanga Fernando, Monash University Accident Research Centre**

Numerous comorbidity studies have been conducted on chronic diseases, including mental ill health, but fewer in the realm of injury. Comorbidity is associated with adverse health outcomes, more complex clinical management, and increased health care costs. In the context of injury, comorbid conditions can delay recovery from injury and increase the risk of complications and death.

The aim of this project is to explore the effect of comorbidity in an injured population with the purpose of providing injury-specific comorbidity indices that will be of practical use in clinical care, epidemiological research and health services planning and financing for injury. The CheReL facilitated this study by linking data from a subset of the NSW Admitted Patient Data Collection (the first occurrence of an injury admission) (the cohort) to other APDC records, NSW RBDM Death Registrations, and Cause of Death Unit Record File.

The indices are expected to be of use to clinicians to estimate injury prognosis, recovery time and possibility of readmissions and to help prevent complications in the presence of comorbid conditions. For administrators, this research will help policy makers to anticipate the effect of population ageing on the burden of injury, as comorbidity prevalence increases steeply with increasing age. It is expected that the indices could be used Australia wide.

Back to top

Impact of low acuity patients on emergency department waiting times, rates of representation, and length of stay when admitted to hospital Dr Alexandre Stephens, Sydney Local Health District

The issue of general practice (GP) type patients attending emergency departments (EDs) instead of primary care has received much media attention in Australia over recent years. Despite suggestions that GP-type patients are contributing to increased ED attendances and crowding, recent evidence

indicates that low acuity patients (LAPs) only account for a small proportion of total ED workload. However, in Australia, it remains unclear what impact LAPs have on ED waiting times, and, importantly, whether a high number of LAPs adversely affects patient health outcomes.

The aim of this project is to evaluate the impact of low acuity, GP-type patients on ED waiting times, rates of representation, and length of stay in hospital when admitted in NSW public hospitals. The CHeReL facilitated this study by linking data from NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection and NSW RBDM death registrations.

This research will attempt to shed light on the issue of GP type patients in EDs, and how their attendance to EDs may impact waiting times and health outcomes for other (more urgent) patients. The results of the project will provide valuable information to inform policy and healthcare services planning.

Back to top

An assessment of appropriate Radiotherapy Utilization (RTU) versus optimal across NSW and ACT Professor Geoff Delaney, Ingham Institute, University of NSW

The Collaboration for Cancer Outcomes Research and Evaluation (Ingham Institute for Applied Medical Research) and others have developed evidence-based benchmark models to calculate the proportion of cancer patients in a population that should receive radiotherapy (RT). The radiotherapy utilisation models (RTU) were based on the indications for radiotherapy that were identified through a systematic review of the literature to create the radiotherapy utilization models for all cancers. The NSW Clinical Cancer Registry contains population-based data on tumour stage and histology as well as treatment details on radiotherapy, surgery and chemotherapy. Further detail obtained through data linkage could be used to customise the existing evidence-based optimal radiotherapy utilization model to NSW and examine factors that affect appropriate use of radiotherapy in NSW.

The aims of this study is to construct a specific NSW RTU model based on NSW specific tumour incidence and stage proportion data; to compare actual uptake and appropriateness of RT with evidence- based benchmarks by tumour stage and other factors available from NSW sources; to examine the proportion of cases whose management complies with EviQ protocols; to examine factors that may affect appropriate care such as patient age, socio-economic status, distance from RT Facility; and also estimate the benefits from increased compliance with guidelines in terms of clinical outcomes and cost. The CHeReL linked data from a cohort of patients diagnosed with cancer and notified to the NSW or ACT Cancer Registries to NSW and ACT Admitted Patients Data Collections, NSW and ACT Death Registrations, Cause of Death Unit Record File, NSW Retrospective Radiotherapy Dataset and NSW Clinical Cancer Registry.

The availability of this data and the expertise of the CCORE research group will provide a unique opportunity to combine efforts to calculate the optimal radiotherapy utilization rates for various cancers and specifically identify areas of shortfall. Further analysis would then enable identification of factors that influence treatment and non-treatment.

Back to top

Evaluation of the NSW State Cardiac Reperfusion Strategy (SCRS) Mr Daniel Comerford, Agency for Clinical Innovation

According to the National Heart Foundation, over 15,000 people in NSW have a myocardial infarction each year and there is a mortality rate of 22% for these people. The New South Wales (NSW) Agency for Clinical Innovation (ACI) has worked with NSW Ambulance to improve cardiac care through the implementation of the State Cardiac Reperfusion Strategy (SCRS).

The aim of this project is to evaluate the implementation of the SCRS. The evaluation will be conducted in 3 stages - assessing the short, medium and long term outcomes of the program. This project aims to collect data to inform the evaluation of the short-term measures along with relevant Activity Based Funding data. The evaluation will focus on key linked pre-hospital and hospital data and include short-term outcomes of mortality and re-hospitalisation.

The cohort was formed by patients who were admitted for Cardiac reperfusion as identified from Cardiac Catheter Laboratories Data, NSW Admitted Patient Data Collection and NSW Ambulance datasets. The CHeReL linked the cohort to the NSW Admitted Patient Data Collection, NSW Registry of Births Deaths and Marriages (Death Registrations), NSW Cause of Death Unit Record File Data Collection and NSW Emergency Department Data Collection.

As the State Cardiac Reperfusion Strategy (SCRS) is rolled out on a state-wide basis, it is important to observe differences in local approaches to service delivery and the level of achievement of outcomes intended for patients, staff and health services. This evaluation will help determine whether NSW SCRS models of care were successfully implemented, including timely access to reperfusion, and whether there were any issues during implementation.

Back to top

Better Evidence for Earlier Identification and Surgical Intervention for Refractory Epilepsy (The BEST Study) Stage 1 Professor Frances Rapport, Australian Institute of Health Innovation

Epilepsy is the most common serious brain disorder, affecting more than 50 million people worldwide. In Australia, 1 in 26 people will develop epilepsy at

some time in their lives. Epilepsy leaves many at increased risk of depression, unable to sustain relationships or employment. Mortality is greatest for those with refractory epilepsy, where seizures cannot be controlled by drugs and where patients may need surgery to reduce or eradicate seizures. However a gap exists between identification of patients and surgery, which is affecting the positive impact of surgery for many.

The overall aim of this study is to examine health services use and treatments for individuals with epilepsy in NSW, including health outcomes for individual who undergo refractory epilepsy surgery in NSW. Stage 1 of this research aims to describe the patient demographics, clinical conditions (eg. other comorbid conditions), examine epilepsy patients' overall hospitalisation use during the 5-year period, and identify health outcomes such as hospital length of stay, 28-day hospital readmission and 30-day mortality. The CHeReL facilitated this study by linking a cohort of individuals with epilepsy (identified from the NSW Admitted Patient Data Collection) to data from NSW RBDM Death Registrations and Cause of Death Unit Record File.

The outcomes of this study should aid in a better understanding of healthcare use and in-hospital treatment costs. A better understanding of health service use will assist highlighting where service improvements, if needed, should be targeted.

Back to top

Health and ageing: The role of primary care in delivering greater health system sustainability
Professor Jane Hall, CHERE, University of Technology

Sustainability of health care is a consistent issue of concern, with expenditure increasing and predicted to double in terms of share of GDP over the next forty years. Primary health care has become a major target for budgetary measures, prompting a renewed interest in the role of primary care in the performance of the Australian health system as well as sustainability of health system demand in the face of an ageing population. In particular, out of pocket costs are advocated by the Australian Government as its primary policy instrument to curtail demand and reduce federal expenditure.

This project aims to develop a better understanding of the drivers of health care use and expenditure, and to determine to what extent health expenditures are associated with patient demographics, and socioeconomic and health status. Specific aims are to develop an overall picture of and identify key drivers of health care expenditure for individual patients; develop econometric models that can predict those who are likely to become a high user of health care; and establish the relationship between primary health care and short and medium term use of other health care services.

The project uses the 45 and Up Study survey data linked to Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data, with these records linked

by the CHeReL to the NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, and NSW Registry of Births Deaths and Marriages death registrations. This project has widespread policy implications and findings will feed into the evidence base informing targeted policies for a sustainable health care system. In particular it will identify the factors associated with high expenditure growth that threaten sustainability plus identify the modifying factors reducing high healthcare expenditure.

Back to top

Does gastrostomy improve the lives of children with severe disability and their families? Professor Julian Trollor, University of NSW

Approximately 750 children are born each year in Australia with a moderate to severe ID and many of these children develop feeding problems. The effects of feeding problems include but are not limited to malnutrition, unreliable delivery of medications, and pulmonary aspiration of food and fluid. One treatment option which is increasingly used is enteral feeding via a gastrostomy tube. Most children will gain weight following gastrostomy insertion but the evidence base supporting this practice is otherwise limited. Neither the risks nor benefits for health arising from gastrostomy feeding have been adequately evaluated; likewise the prevalence of complications or effects on child and family health in terms of hospitalisations and costs has not been formally assessed.

This project aims to investigate the outcomes before and after gastrostomy in children with moderate and severe ID. Specifically it aims to estimate the incidence of gastrostomy insertion; examine accessibility to gastrostomy services; and calculate health care costs of feeding difficulties including gastrostomy use.

For this study the CHeReL linked data from the Disability Services Minimum Dataset to: the NSW Admitted Patient Data Collection; NSW Mental Health Ambulatory Data Collection; NSW Emergency Department Data Collection; Corrective Services; Statewide Disability Services data; Targeted Specialist Education Services data held by the NSW Department of Education; and data from the NSW Public Guardian and NSW Ombudsman.

This research will contribute to the evidence base of benefits and/or risks of the gastrostomy procedure and assess survival following gastrostomy, thereby informing treatment options for children born with moderate to severe ID.

Back to top

Medicines Post-Marketing Surveillance Using the 45 and Up Study and Linked Services Datasets Dr Claire Behm, Director, Signal Investigation Unit, Therapeutic Goods Administration

Systematic post-marketing monitoring of adverse drug reactions (pharmacovigilance) is essential for the protection of patient safety and is an important public health function undertaken by the Therapeutic Goods Administration. Whilst sophisticated, current surveillance practices have certain limitations including under-reporting and the absence of risk quantification. Re-purposed observational data, derived as a by-product of administrative processes, provide a longitudinal record of the majority of health care encounters in Australia for large patient populations. Linkage between observational datasets permits the use of real world data to assist in the evaluation of potential harms associated with medicines.

The aim of this project is to assess the feasibility of analysing routinely collected data, augmented with self-reported lifestyle and health data, in order to inform pharmacovigilance in Australia. It will endeavour to describe drug utilisation within the cohort, while assessing whether analysis of routinely collected administrative data, can be used to corroborate known associations between medicines and adverse reactions and to quantify risk.

This project was formed by a cohort of participants selected from the Sax institute's 45 and Up Study. This data set also includes Department of Human Services data from the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS). The CHeReL facilitated this project by linking the 45 and Up cohort to NSW Admitted Patient Data Collection, ACT Admitted Patient Collection, NSW RBDM Death Registrations, ACT BDM Death Registrations, NSW Cause of Death Unit Record File, NSW Emergency Department Data Collection, ACT Emergency Department Data, NSW Central Cancer Registry and ACT Cancer Registry. ACT Cause of Death Unit Record File is provided directly by ACT Health.

If analysis of these linked data sets is found to be feasible for TGA purposes, the investigators will seek to extend the project to investigate signals that have been detected but not yet verified, in order to support existing medicines surveillance. This is likely to have significant benefits to public safety.

Back to top

Estimating survival and cost of hospitalisations following cardiovascular disease events Professor Andrew Hayden, University of Technology

Since the 1970s life expectancy has been increasing by about a year each decade, mainly due to declines in cardiovascular disease (CVD). This can be partly attributed to the uptake of drugs to reduce high blood pressure and cholesterol. Government expenditure on the Pharmaceutical Benefits Scheme (PBS), which provides subsidies for many commonly used medications, has almost doubled in real terms during the past decade. An important driver of this rise in expenditure has been the widespread use of cardiovascular drugs such as statins. Simulation models are increasingly used to estimate the likely impact of interventions on the long term progression of chronic diseases. However,

existing policy models are unlikely to capture important systemic trends in the prevalence and outcomes of CVD.

This project aims to develop a simulation model to inform policies to promote the cost-effective use of cardiovascular medications. It sets out to determine survival after hospitalisation for CVD in Australia by examining differences in survival by demographic factors such as age and sex, socioeconomic status and type of CVD. It will also determine the cost of different CVD events in the acute phase and long term in relation to these patient characteristics. In order to identify all patients admitted to hospital with a CVD diagnosis and any person who has died from CVD, the CHeReL linked data sets from NSW Admitted Patient Data Collection, NSW RBDM Death Registrations and Cause of Death Unit Record File.

This simulation model will be utilised to predict life expectancy, lifetime Quality Adjusted Life Years and lifetime costs for different disease management options and hence can be used for cost-effectiveness and cost-utility analysis. The results of this study will inform policies to promote the cost-effective use of CVD medications in an era when a range of low cost generic drugs are available to treat established risk factors.

Back to top

Improving Care Standards and Costs for Spinal Trauma Patients Dr Lisa Sharwood, University of Sydney

Traumatic spinal cord injury (TSCI) is a devastating injury with serious lifelong consequences for its survivors. The costs of this injury to the health care service and therefore the tax payer are significant, and evidence has shown that failure to provide the right care for the patient with TSCI can directly impact on costs. Deficits in clinical policy and practice can escalate personal and economic costs for patient as well as the health care system.

Both evidence and anecdote suggest there remains significant variation in policy and practice among what is considered ‘best practice’ specialist care, including referral patterns to specialist centres and the timing of surgical intervention.

This project seeks to determine whether the standard of care provided at a selection of Major Trauma Services are consistent with expertly defined, multi-disciplinary standards across the acute post-injury phase of TSCI care. In addition, to quantify the degree to which variation in clinical practice and institutional performance impacts on patient outcomes and acute care costs, and is amenable to change.

This project will examine a record linkage cohort of patients over 16 years of age who sustained TSCI in the state of NSW. The CHeReL facilitated this project by providing a linkage between the Access to Care data collection and data from

the NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, NSW RBDM death data and Cause of Death Unit Record File.

This analysis will provide an accurate estimate of health expenditure across the acute phase of care for an incident cohort of TSCI patients. Identification of specific deficits will facilitate the application of targeted improvement strategies, aiming for greater efficiencies of our services, focused resource use, highest standard of practice and consequently optimal outcomes.

Back to top

Examining the long term effects of the 2001 heroin shortage Dr. Kevin Schnepel, University of Sydney

A large reduction in the supply of heroin in early 2001 led to the substantial decline in heroin use in NSW and other states. Studies have shown that there were fewer heroin overdoses and more drug treatment in 2001, however there is also evidence that heroin users switched to other illicit drugs. Governments devote substantial resources to reducing the consumption of illicit drugs (Moore, 2008). However, there is little information about what happens when supply is reduced.

The aims of this project is to estimate the long-term health and crime outcomes for individuals known to be using heroin prior to 2001 through their contact with police or the health care system. Specifically, to estimate the change in heroin users' criminal activity and health outcomes after 2001, to assess whether heroin users switched to other drugs and document what these drugs were, and to examine if there were heterogeneous outcomes based on demographic characteristics or other factors (e.g. criminal history).

To facilitate this study the CHeReL linked data from NSW Admitted Patient Data Collection, NSW RBDM Death Registrations, Cause of Death Unit Record File, NSW Emergency Department Data Collection, NSW Mental Health Ambulatory Data Collection, NSW Bureau of Crime Statistics and Research Reoffending Database and the Pharmaceutical Drugs of Addiction System.

Combining high quality administrative data on heroin users with a large and unique shock to the supply of heroin provides an opportunity to better understand the longer-term benefits and costs of decreasing the availability of addictive illicit drugs – results which will be of widespread interest to economists, other academics and policy makers, both in Australia and internationally.

Back to top

Measuring Low Value Care: Indicator Design and Application Associate Professor Adam Elshaug, University of Sydney

There are strong clinical, ethical and economic imperatives for identifying waste in healthcare systems. In recent years, there has been exponential growth in research aimed to measure, and reduce the use of health care services that provide little to no benefit. Studies from the US have highlighted that the value of many services depends on the clinical situation in which they are provided. Several 'lists' compiled by prominent global health organisations have identified health services as low-value in specific clinical circumstances. Despite this, data on Australia's level of low-value services is sparse.

The aim of this study is to develop indicators for selected low-value services applicable to Australia's health care setting and routinely collected health data. Furthermore to apply these indicators to examine the proportion of patients receiving low-value services, the rates of low- value service use, the variation in low-value care according to the provider and patient characteristics, and the proportion of government and patient spending devoted to low value services. To facilitate the study, the CHeReL linked hospital separation data from the NSW Admitted Patient Data Collection.

This project is the first of its kind in Australia and will lead the next phase of measuring low-value, potentially harmful care within large-scale representative datasets. This work is fundamental in order to deliver safe, effective and cost-effective care.

2016

Back to top

Actual versus optimal radiotherapy utilization in cancer patients in NSW Dr Mei Ling Yap, Cancer Council NSW

Radiotherapy is a cost effective cancer treatment which can be used to cure, reduce loco-regional recurrence from cancer, or to palliate distressing symptoms. Indications for use of radiotherapy are defined in evidence based treatment guidelines issued by major national and international organisations, and it is estimated that the optimal utilisation rate is 48% of new cases of cancer should receive radiotherapy. However actual radiotherapy utilisation rates are well below this. In addition, very few studies have calculated actual utilisation from individual patient data.

This project therefore aims to investigate the actual radiotherapy utilisation rate in NSW for curative and palliative treatment using the 45 and Up Study population and investigate the socio-demographic characteristics which affect radiotherapy utilisation and survival after a cancer diagnosis. Additionally it will examine trends in radiotherapy utilisation over time and compare the actual rate of utilisation with the optimal rate.

For this project the CHeReL linked data from the 45 and Up Study to the NSW Admitted Patient Data Collection, the NSW Cancer Registry, the NSW Emergency Department Data Collection, the NSW RBDM death registrations and the Cause of Death Unit Record File. Data from the Department of Human Services Medicare Benefits Schedule and Pharmaceutical Benefits Scheme claims were provided with the 45 and Up Study data and were used to identify radiotherapy treatments, along with the NSW Admitted Patient Data Collection.

Results from the study will provide valuable information to clinicians on actual radiotherapy utilisation rates, plus help to identify which groups of cancer patients are not accessing radiotherapy. This information will feed into radiotherapy services planning, and policy initiatives to improve access to radiotherapy treatment.

Back to top

Calibrating and validating parameterised simulation models of the development, prevention and treatment of cancer using cost and outcomes data from the 45 and Up Study Prof Karen Canfell, Cancer Council NSW

The Cancer Council NSW has developed simulated mathematical models that are able to predict, given certain parameters, future cancer-specific outcomes for NSW or the Australian population. The aim of these modelling studies is to predict the effectiveness and cost effectiveness of prevention and treatment interventions to reduce the cancer burden. This current project seeks to calibrate, optimise and validate these models using factors relating to cancer incidence, care and outcomes in the 45 and Up Study.

The specific aims of this project are to quantify the cost of cancer to the healthcare system across the cancer journey characterised by health-related and socio-demographic factors and incorporate these costs into the simulation models; plus optimise the cancer specific simulation models using aggregated incidence, mortality, screening behaviour, diagnosis, treatment, lifestyle and demographic factors that influence cancer outcomes.

For this project the CHeReL linked data from the 45 and Up Study to the NSW Admitted Patient Data Collection, the NSW Cancer Registry, the NSW Emergency Department Data Collection, the NSW RBDM death registrations and the Cause of Death Unit Record File. Data from the Department of Human Services Medicare Benefits Schedule and Pharmaceutical Benefits Scheme claims were provided with the 45 and Up Study data.

The 45 and Up Study will provide important inputs to the natural history models of several cancer types. When informed by these and other data, these models will be used to support healthcare policy, improve prevention, diagnostic and treatment strategies, and inform decision-making to address inequalities in

cancer care. These models can also be used to support information for clinical decision making.

Back to top

Prescribed medicines use and outcomes in Australian Government Department of Veterans' Affairs (DVA) clients Professor Sallie-Anne Pearson, Centre for Research Excellence (CRE) in Medicines and Ageing University of Sydney

The Centre for Research Excellence in Medicines and Ageing was established under a grant from the NH&MRC, with the objective of generating quantitative evidence on the use, safety, costs and cost effectiveness of ageing-related medicines; and to work with agencies to utilise this evidence in policy formulation, evaluation and decision making, plus build national workforce capacity in pharmaco-epidemiology research and policy translation. Professor Sallie-Anne Pearson, Centre for Research Excellence (CRE) in Medicines and Ageing University of Sydney

This application sought to establish a program of research to investigate the use and impact of prescribed medicines in Australian Government Department of Veteran's Affairs (DVA) clients. A pre-existing data set, linked by the CHeReL, was prepared following an approval to undertake a similar program of work on the use and impact of cancer medicines in DVA clients. The current application sought permission to use an existing dataset of DVA client data linked to the NSW Admitted Patient Data Collection, the NSW Emergency Department Data Collection, the NSW Cancer Registry, and death registrations from the NSW Registry of Births Deaths and Marriages and ABS Mortality Data.

The findings from this program of work will generate evidence on the characteristics of treatment populations, durations of medicines use and variation in treatment patterns, in turn facilitating benchmarking against best practice guidelines and the establishment of appropriate treatment in specific populations and settings. Cohort studies will assess outcomes against exposure to specific medicines, and will enable assessment of the benefits and risks of specific treatments. It will also be possible to undertake post-marketing surveillance of medicines to assess safety, efficacy and quality; key parameters for initial and continuing registration of medicines in Australia.

Back to top

Poor Diagnostic Recognition of Intellectual Disability among Mental Health Clinicians Dr Tony Florio, University of NSW

People with Intellectual Disability (ID) have increased rates of mental illness compared to the rest of the population. However diagnostic overshadowing -

which occurs when the presence of an ID in itself distracts clinicians from detecting other health concerns - means that many people do not receive the mental health services they require. Diagnostic overshadowing is due to a lack of, or incorrect, knowledge about ID and the operation of a bias in clinical decision making, where the mental health clinician attributes observed symptoms to the ID and therefore rules out the presence of a mental disorder.

Less well understood is the impact of poor diagnostic recognition of mental health clinicians in recognising a diagnosis of ID. The same lack of knowledge probably contributes to this as to diagnostic overshadowing. Therefore the aims of this project are to examine the rates of diagnostic recognition of ID by mental health clinicians, and to examine how diagnostic recognition interacts with and impacts on diagnostic overshadowing in mental health services.

Using the Mental Health Inpatient dataset, for this study the CHeReL linked records of a sub cohort of people with a known disability from the Disability Services Minimum Dataset held by Family and Community Services, to the NSW Admitted Patient Data Collection and the NSW Emergency Department Data Collection; plus the NSW RBDM death registrations and the ABS Mortality Data. All other records of people in the Mental Health Inpatient dataset not in the sub cohort were used as a comparison group.

Accurate diagnosis is a cornerstone of clinical practice. Misdiagnosis and non-diagnosis of mental disorders and/or ID by mental health clinicians adversely affects mental health clinical outcomes, increases health service expenditure and negatively impacts on quality of life for people with an ID and their carers. By exploring diagnostic accuracy and factors which relate to better diagnostic accuracy, this project will provide data which can be used to develop strategies to promote more accurate diagnosis and thereby improve health outcomes.

Back to top

Comparing mortality rates in people with autism spectrum disorder to the general population in NSW
Professor Julian Trollor, University of NSW

Developmental disability is a term used to refer to a range of conditions, including neurodevelopmental disorders such as ID and ASD (for this project collectively referred to as intellectual and developmental disorders (IDD)). People with IDD experience significant health inequality compared to the general population – including poorer mental health status, lower life expectancy, poorer physical health across a range of body systems, such as oral and gastrointestinal disorders, increased respiratory tract infections and vision and other sensory impairment. In general the health needs of people with IDD are poorly met, with many health professionals feeling they lack the necessary skills to treat this population group.

In order to develop and deliver the most appropriate and effective services for these individuals, a thorough understanding of the current health circumstances

facing this population is needed. Specifically, examination of mortality and cause of death is of central importance for understanding the extent and nature of health inequalities for people with IDD. Therefore, this project aims to determine mortality rates and years of productive life lost in people with IDD, and to compare cause of death and potentially avoidable deaths to those in the general population.

The cohort with IDD were primarily identified from the Disability Services Minimum Data Set and linked by the CHeReL to the NSW Admitted Patient Data Collection and the NSW Emergency Department Data Collection; plus the NSW RBDM death registrations and the Cause of Death Unit Record File.

An understanding of deaths in an Australian context will provide crucial information about the need to target specific health conditions in a preventative manner for this population. The results will offer important information to relevant professionals, service providers, policymakers, family members and individuals with IDD themselves, enabling rapid improvement in meeting the health needs of people with IDD.

Back to top

Variations in treatment modality, health services use and outcomes in breast cancer Associate Professor Bette Lieu, University of New South Wales

Breast cancer treatment and the recommended treatment modality depends on several factors; the type, stage and receptor status of the cancer, extent of spread, prior cancer diagnoses and treatments, age and general health, and personal preference. Further information on the variations in treatment (medications and surgery) provided to women with a diagnosis of breast cancer may assist in identifying populations or areas where more breast cancer support services are required.

The aim of this study is to describe the pattern of treatment modalities provided to women with incident breast cancer and the determinants of those modalities, and to examine the impact of a diagnosis of breast cancer on psychological well-being. Specifically, to estimate the incidence of breast cancer in both men and women in the 45 and Up Study; to explore associations between women's breast cancer treatment modality and a range of demographic, lifestyle, health and screening history and tumour characteristics; In women who have a mastectomy, to identify determinants of the receipt of reconstructive surgery; and to examine the relationship between a diagnosis of breast cancer and psychological distress.

The results of this study will contribute to knowledge of the treatment modalities and the influences on choice of modality experienced by women with breast cancer and the impact of the diagnosis on their psychosocial and physical wellbeing. It will provide further information on patterns of breast cancer treatment and adherence to treatment guidelines. Additionally, identifying

groups who may be most at need of efforts to improve support and treatment, identification of the emotional impact of a breast cancer diagnosis and further quantification of the incidence of breast cancer in particular community groups will be of immediate benefit.

Back to top

Alcohol related problems and the burden on health and law enforcement services: A retrospective data linkage cohort study Dr Amy Peacock, National Drug and Alcohol Research Centre, University of New South Wales

Alcohol consumption is a leading cause of death and disability globally, with increasing alcohol-related harms despite overall stable rates of consumption placing a greater burden on healthcare and law enforcement services. However, there is limited information on the magnitude of health and other risks for people with alcohol related problems, and the impact of these at the population level is poorly understood, particularly in terms of individual characteristics, and levels of morbidity, mortality, and other adverse outcomes such as engagement with the criminal justice system. Medical conditions such as cancer warrant additional scrutiny with regards to understanding common comorbidities alongside alcohol use problems.

This project will address key gaps in our understanding of mortality, morbidity, offending and incarceration amongst people with an alcohol-related problem. Specifically it will describe the numbers, characteristics and service settings for people presenting to healthcare services with an acute alcohol harm or problematic alcohol use; and identify rates and predictors of mortality, morbidity, offending and incarceration. It will also explore the comorbidity of alcohol use and cancer, predictors of developing cancer, and mortality due to cancer, to identify where a cancer diagnosis fits in the trajectory of alcohol related problems.

The CHeReL Linked records from the NSW Admitted Patient Data Collection and the NSW Emergency Department Data Collection to identify a cohort of people with at least one emergency department or hospital presentation for alcohol related harm. These records were then linked to the NSW Re-offending data based from the NSW Bureau of Crime Statistics and Research, plus the NSW Central Cancer Registry, the NSW Mental Health Ambulatory Data Collection, the NSW Registry of Birth Deaths and Marriages death registrations, and the Cause of Death Unit Record File.

Findings from this project will lead to improved knowledge regarding alcohol related harms. Results will guide policy to routinely implement screening and intervention in healthcare settings and enable health professionals to better identify those at risk of adverse outcomes. Findings will also highlight the

potential protective effects of mental health treatment in the community and areas where prevention efforts can be directed.

Back to top

Health Care Costs of People with an intellectual and developmental disability Professor Julian Trollor, University of New South Wales

This project will use linked administrative data to evaluate differences in health services utilisation and costs for the IDD population group compared to published data from the NSW general population, and will draw comparisons between subpopulations within these groups (such as those with mental health problems, ASD, Down syndrome or cerebral palsy). The overall objective is to inform policy around appropriate funding models and help to identify gaps in current service provision for people with IDD or with mental health ill health.

With the full roll-out of the NDIS to begin from July 2016, cost and service use estimations from APDC, EDDC and MH-AMB will be of use in planning and supporting health and cross-sector service provision. This will be particularly important in areas experiencing rapid change such as the Hunter NDIS trial site, which is also grappling with planning and execution of the closure of large residential facilities for people with IDD.

Back to top

Improving NTD ascertainment in NSW: supplementing data for a national incidence study from linked records Dr Lisa Hilder, National Perinatal Epidemiology and Statistics Unit (NPESU)

The purpose of this study was to utilise data linkage to improve data quality and case ascertainment for neural tube defects (NTDs) in NSW. NTD data from the NSW Registry of Congenital Conditions (NSW RoCC) contributed by NSW to a national study the incidence of NTD before and after mandatory fortification of flour in bread was incomplete by up to 40%, particularly for pregnancies ending in termination of pregnancy before 20 weeks gestation and 27% of those cases that were provided had missing information about maternal age and/or maternal Indigenous status.

NSW Admitted Patient Data Collection (APDC) data cannot discriminate between NTD and non-NTD central nervous system (CNS) conditions in pregnant women with a known or suspected fetal anomaly, so data for this linkage used CNS cases from source datasets. CHeReL undertook two data linkages: data from the APDC about pregnant women with a fetus known or suspected to be affected by a CNS anomaly (APDC-pregnancies) and Perinatal Data Collection (PDC) data linked by mother with RoCC records with a CNS anomaly; and data from the NSW Perinatal Deaths Review (PDR), neonatal admissions from with a

CNS anomaly and Perinatal Data Collection (PDC) data linked by baby with RoCC records with a CNS anomaly. This resulted in four case groups: APDC-baby and/or PDR cases linked by baby with a RoCC case; APDC-pregnancy cases linked by mother with a RoCC case; APDC-baby and PDR records not linked with a RoCC case; and APDC-pregnancies not linked with a RoCC case. RoCC data can include both a mother and a baby identifier and will be used to reconcile cases with both a mother and a baby linkage. APDC-baby records and PDR records can be separated into NTD and non-NTD anomalies. Further information will need to be sought using site-specific data collections for APDC-pregnancy records to enumerate additional NTD cases.

Back to top

Concord Health and Ageing in Men Project (CHAMP) – Data Linkage Professor Robert Cumming, University of Sydney

The Concord Health and Ageing in Men Project (CHAMP) was established to investigate the consequences and inter-relationships of the major geriatric syndromes for men aged 70 years and over, namely falls, fractures, cognitive impairment and dementia, urinary symptoms and incontinence, and poor mobility and functional dependence. Men are followed up intermittently and undertake self-completed questionnaires and clinical assessments to determine physical, neuropsychological and biological functioning.

In order to enrich the understanding of health trajectories for men of this age group, CHAMP data were linked by the CHeReL to the NSW Admitted Patient Data Collection, NSW Cancer Registry, ABS Mortality Data and NSW Registry of Births Deaths and Marriages death registrations. Data linkage to the CHAMP cohort has provided the opportunity to study the health status of participant's over the continuum rather than just intermittently at follow up, offering the potential to substantially value-add and extend the available data for investigation. Linkage to disease data from the NSW Cancer Registry, plus hospital and mortality data will facilitate investigations that contribute to the understanding of the risk, protective, social and environmental factors that influence disease, disability and death. Finally, the linkage with routinely collected data has added the potential to identify new and innovative research questions that could not be otherwise investigated.

Back to top

Diabetes case detection through Emergency Department admissions Associate Professor N Wah Cheung, University of Sydney and Westmead Hospital

Hyperglycaemia is common amongst patients who are admitted to hospital through the Emergency Department, many of whom were not previously known to have diabetes. There is research to show that hospital patients with recently detected hyperglycaemia have poor follow up, despite the evidence from other

studies demonstrating that many people are diagnosed with diabetes on follow up testing. Failure to properly assess people with hyperglycaemia in the Emergency Department is a missed opportunity to diagnose a population at risk and implement treatment which may improve outcomes.

This study aims to determine if routine glucose screening in the Emergency Department combined with an automated HbA1c testing and notification to Diabetes Services for those who are hyperglycaemic, leads to improved detection and follow up of diabetes as a result of the hospital admission. Specifically, the study will establish a system of routine blood glucose measurement in the Emergency Department and investigate if the system leads to improved outcomes.

In total 18 hospitals across NSW are involved in this cluster randomised trial. Data from people attending participating hospitals and having a blood glucose level taken were recorded and a case list prepared. For efficiency and accuracy additional patient details were obtained from the NSW Admitted Patient Data Collection (APDC). To provide these additional details the CHeReL extracted records for the case list from the Master Linkage Key for the NSW APDC and deaths from the NSW Registry of Births Deaths and Marriages and the Australian Bureau of Statistics.

This project presents an opportunity to improve outcomes for people at high risk due to undiagnosed diabetes. Results from this study will also inform clinical guideline recommendations from the Endocrine Network of the Agency for Clinical Innovation.

2015

Back to top

The utilisation of antihypertensive drugs during Pregnancy and the risk of adverse outcomes for mothers and their children Dr Alys Havard, Centre for Big Data Research in Health, UNSW Sydney

The primary goal of antihypertensive treatment in pregnancy is to avoid maternal and neonatal morbidity by limiting progression to severe hypertension. Management of mild to moderate hypertension during pregnancy (HDP) is less clear and clinical practice generally varies. The available literature on utilisation of antihypertensive drugs in pregnancy is scarce and there is no clear evidence of reduced risk of maternal, obstetric and neonatal outcomes.

This study aims to investigate the gaps and limitations in the utilisation and safety of antihypertensive agents during pregnancy. Specifically it will measure antihypertensive agent prescribing rates, patterns and trends, and adherence to medications during pregnancy in women with chronic hypertension; evaluate

initiation rates for antihypertensive drugs for gestational hypertension and preeclampsia; and investigate use of specific medications and their role in adverse maternal, neonatal and infant outcomes compared to normotensive mothers or women not treated with medications.

To facilitate this study the CHeReL linked records from the NSW Perinatal Data Collection, the NSW Admitted Patient Data Collection, the NSW Emergency Department Data Collection, the NSW Register of Congenital Conditions, the NSW RBDM births and death registrations, and the ABS Mortality Data. The CHeReL also provided the Australian Institute of Health and Welfare with personally identifiable variables from NSW data collections for linkage to the Pharmaceutical Benefits Scheme.

This study will generate evidence regarding prescribing patterns for the management of hypertension in pregnancy. Moreover, as there is uncertainty regarding the risks and benefits associated with the use of antihypertensive drugs during pregnancy, this study will be important for informing guidelines regarding the prescription of antihypertensives during pregnancy.

Back to top

Comparative Effectiveness of 5-FU based chemotherapy for Colorectal Cancer Patients Professor Marie Ranson, Illawarra Health & Medical Research Institute, University of Wollongong

Colorectal cancer (CRC) is currently the second most common cancer in NSW, accounting for 13% of new cancer cases in 2008. The high prevalence and severe impact of CRC in older populations makes it a large and increasingly important target for improved treatments in an increasingly ageing population. Since the late 1950s, chemotherapeutic treatment of CRC has centred on the use of the fluoropyrimidine 5-fluorouracil (5-FU). Despite the long history of 5-FU use, there is still no universally recognised standard treatment regimen and each appear to be associated with differing toxicity profiles for 5-FU. While many clinical trials and randomised cross-over trials have quantified information on side effects, efficacy and preference, few studies have been conducted that follow-up on patients treated in practice. Retrospective practice-based research can provide important findings that are not revealed in clinical trial studies due to stringent compliance rules and strict inclusion and exclusion criteria (notably the exclusion of patients 70 years and older).

Information collected by Local Health District (LHD) Clinical Cancer Registries was potentially useful for determining the comparative effectiveness of chemotherapy regimens through analysing patient data of all individuals diagnosed with colorectal cancer in NSW. This study therefore set out to determine which chemotherapy regimens for CRC are administered most frequently in NSW, whether the type of chemotherapy treatment prescribed is associated with the diagnostic and demographic details of the patient, and

whether there is a survival advantage by taking a particular chemotherapy regimen.

For a cohort of patients diagnosed with colorectal cancer, between 2006 and 2015, six Local Health District Clinical Cancer Registries (South Eastern Sydney LHD, Hunter New England LHD, Northern Sydney LHD, South Western Sydney LHD, Mid North Coast LHD, Western Sydney LHD) were linked by the CHeReL to the NSW Admitted Patient Data Collection, NSW Registry of Births, Deaths & Marriages (death registrations) and ABS Cause of Death Unit Records File. The results of this study will provide the first large scale report on current prescribing habits for colorectal cancer chemotherapy, as well as information on treatment effectiveness in practice.

Back to top

Perinatal exposures and childhood outcomes Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

This project aims to investigate the long term effects of perinatal exposures on child health and development. Given a significant proportion of brain growth, development, networking and synapse formation occurs during the last six weeks of gestation, these late pregnancy exposures may increase the risk of incomplete brain development and subsequent neuro-cognitive impairments.

The five studies proposed within this project will investigate child health and development outcomes for children exposed to preterm labour rupture of membranes in utero, or exposed preterm labour with and without preterm birth; evaluate low birthweight as an indicator of the quality of maternity care; and will examine outcomes following breech presentation at term by mode of delivery; and outcomes following laser surgery for twin-twin transfusion syndrome. For each study the frequency and trends of each exposure will be described, and child health outcomes, early childhood development and disability, and educational outcomes will be explored.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets used in this study were the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection; the NSW Register of Births Deaths and Marriages birth and death registrations; the NSW Pharmaceutical drugs of addiction system; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

This project provides the opportunity to examine the long term effects of perinatal exposures in a large population cohort. Findings will generate valuable information to inform maternity practice and the development of initiatives to improve child health and education outcomes.

Back to top

Risk prediction modelling for lung and breast cancer outcomes in the 45 and Up Study Dr Marianne Weber, Cancer Council NSW

Lung and breast cancers are among the most commonly diagnosed cancers in Australia and also account for a high number of cancer-related deaths. Whilst there is an established screening program for breast cancer in Australia, cancer screening can be controversial, with the number of lives saved through early diagnosis weighed against potential over-diagnosis and over-treatment of indolent tumours. There is not yet a recommended program of lung cancer screening in Australia.

Risk prediction models aim to determine the absolute risk or probability of future events, using different combinations of predictor variables in a well-defined population. There is some evidence that risk prediction tools such as the PLCOm2012 have the potential to significantly optimise lung cancer screening by reducing harms and increasing cost-effectiveness; however risk prediction models for breast cancer have to date had poor discriminatory accuracy.

The overall objective of this project is to explore the potential of validating and developing risk assessment tools for predicting cancer incidence and mortality using the 45 and Up Study. The project aims to initially validate risk prediction models for lung cancer, validating the PLCOm2012 specifically, then validate and develop models for breast cancer using similar methodology.

For this project the CHeReL linked data from 45 and Up Study to the NSW Admitted Patient Data Collection, the NSW Cancer Registry, the NSW Emergency Department Data Collection, the NSW RBDM death registrations and the Cause of Death Unit Record File. Data from the Department of Human Services Medicare Benefits Schedule and Pharmaceutical Benefits Scheme claims were provided with the 45 and Up Study data.

The outcomes of this project will address gaps in evidence for decision making around lung and breast cancer screening in the Australian setting, and will provide evidence-based, clinically relevant information on identifying high risk individuals that will benefit most from early cancer detection strategies and those at low risk of disease who can potentially avoid invasive screening.

Back to top

Surveillance of hospitalisations, hepatocellular carcinoma and mortality among people diagnosed with hepatitis C or hepatitis B virus infection in New South Wales: A population-based linkage study Dr Jason Grebely, Kirby Institute, University of NSW

In Australia, infection with hepatitis C virus (HCV) or hepatitis B virus (HBV) is associated with increased morbidity, mortality and health-related costs. Fortunately, effective treatment for both infections is available and is associated with the prevention of HCV and HBV-related morbidity and mortality. This project established an annual prospective population based surveillance system for monitoring hospitalisations, hepatocellular carcinoma and mortality among people diagnosed with HCV or HBV infection in NSW. Trends were evaluated and populations at increased risk of HCV and HBV-related morbidity and mortality were identified, generating important data for informing future policy towards the reduction of HCV and HBV burden in NSW. A central question important for policy makers is whether these programs will have an impact on morbidity and mortality at a population level. The proposed estimates of hospitalisations, hepatocellular carcinoma and mortality will also provide the most accurate estimates to inform future mathematical modelling of various strategies for tackling the HCV and HBV epidemics.

The study examined linked routinely-collected health administration datasets to assess morbidity and mortality among people with an HCV or HBV notification. The CHeReL linked the cohort data from the Notifiable Conditions Information Management System (HCV and HBV diagnoses 1993-2012) with NSW Admitted Patient Data Collection, NSW Central Cancer Registry (hepatocellular carcinoma), Cause of Death Unit Record File, NSW Registry of Births Deaths and Marriages (death registrations, HIV administrative dataset, and the Pharmaceutical Drugs of Addiction System (opioid substitution treatment).

This study provides a framework for the development of a surveillance mechanism for assessing HBV and HCV-related hospitalisations, hepatocellular carcinoma and mortality. It has significant potential to inform best practice in prevention of future morbidity and mortality related to HBV and HCVs infection and program strategy implementation at a population level.

Back to top

Health service utilisation before and after a diagnosis of cancer: a data linkage study using the 45 and Up Study cohort. Professor Jane Young, Cancer Institute NSW and University of Sydney

The following projects constitute a program of work to quantify health service use in a cohort of people with cancer in NSW, before and after a cancer diagnosis. The aim is to inform future initiatives to streamline care pathways and improve cancer care services outside of hospital settings. Patterns and variation in health service use before and after a cancer diagnosis will be derived for people with cancer in the 45 and Up study as well as a control group, for all cancers and for specific cancer sites.

All participants in the 45 and Up Study were linked by the CHeReL to the NSW Central Cancer Registry to form the study cohort. These records were then

linked by the CHeReL to the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection; the NSW Clinical Cancer Registry and the NSW Registry of Births Deaths and Marriages and ABS Mortality Data. Data from the Medicare Benefits Schedule and the Pharmaceutical Benefits Scheme, linked to records in the 45 and Up Study, were also included in the final cohort.

Back to top

Primary care quality, patterns of use and its impact on health outcomes and costs. Associate Professor Kees Van Gool, CHERE, University of Technology

In the face of a rapidly ageing population combined with increasing chronic disease and patients with complex health needs, there is increasing pressure on the health care system and its future ability to maintain efficient effective services that meet the needs of patients. Current health systems are largely designed around treating acute episodes of illness; however there is a growing recognition that health systems need to transform to systems with a greater emphasis on the prevention and management of chronic conditions. High quality, evidence-based, primary care can delay or prevent the onset of complications for many chronic conditions such as diabetes, congestive heart failure and asthma; thereby potentially reducing emergency department (ED) visits and hospitalisations. However, there is still much uncertainty around the role of primary care and its potential impact on health outcomes.

This project aims to examine the relationship between primary care use and quality and health outcomes and health care costs. Specifically it will investigate if the regularity of visits to their GP and greater continuity of GP care will affect the use of evidence based care, downstream health care use and costs, and health outcomes. The project uses the 45 and Up Study survey data linked to Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data, with these records linked by the CHeReL to the NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, and NSW Registry of Births Deaths and Marriages death registrations.

This research will be of high policy significance because it will create new knowledge about the role of primary care and subsequent health and economic outcomes. Results will be of relevance to policy makers who are looking to the primary care sector becoming a central focus of the health care system to deliver improved health outcomes and efficiencies.

Back to top

Outcomes of knee replacement surgery Professor Fiona Blyth, The Sax Institute

Rates of knee replacement surgery are rising, reflecting underlying trends in population ageing and obesity despite overseas evidence that a significant proportion of people undergoing knee replacement surgery continue to

experience poor functional outcomes. This has not been assessed in the Australian setting.

This project aims to investigate outcomes from knee replacement surgery using 45 and Up Study participants. Specific aims include investigation of the extent to which those who have had knee replacement surgery report poor physical functioning; identify which socio-demographic, health behaviour and health status variables are associated with poorer self-reported physical functioning; and to compare self-reported physical functioning, use of Medicare Benefits Schedule (MBS) funded services, and use of prescription medication's in those who have had knee replacement surgery versus a comparison group who have not.

The CHeReL linked data from the 45 and Up Study, which includes MBS and Pharmaceutical Benefits Scheme (PBS) data, to the NSW Admitted Patient Data Collection. MBS and PBS data provided data on the volume of MBS funded services and dispensing of PBS listed analgesic medications.

Knee replacement surgery will be used increasingly to manage severe osteoarthritis of the knee as the population ages. Thus the identification of potentially modifiable risk factors for poor functional outcomes in the Australian context is likely to inform future attempts to optimise health outcomes.

Back to top

Investigation of male urinary, prostatic and sexual health Professor Emily Banks, Australian National University

Adverse prostatic and male sexual health conditions, particularly benign prostatic hyperplasia and erectile dysfunction, are common and responsible for considerable morbidity and health care costs. However there is limited evidence on the factors associated with prostatic and male sexual health conditions and related surgical procedures, and limited direct evidence of the impact of prescription medications on clinical outcomes using linked prescription data.

Therefore this study aims to investigate the potentially modifiable factors influencing adverse male urinary, prostatic and sexual health indices and the factors influencing outcomes following related surgical procedures. The study will investigate lifestyle, demographic, medication and baseline health factors, focusing specifically on benign prostatic hyperplasia; urinary incontinence, related surgical procedures and quality of life, disability and mental health measures using participants from the 45 and Up Study. The CHeReL linked records from the NSW Admitted Patient Data Collection, NSW Registry of Births Deaths and Marriages death registrations; and the NSW Central Cancer Registry to the 45 and Up Study. Records from the 45 and Up Study were linked to records from the Department of Human Services Medicare Benefits Schedule and Pharmaceutical Benefits Scheme by the Sax Institute.

Information on the factors relating to morbidity and health care cost associated with male urinary, prostate and sexual health is limited nationally and internationally. Therefore this study will add substantially to the existing evidence and will provide valuable information for clinical practice and policy initiatives.

Back to top

Care pathways for people with lung cancer Professor Jane Young, Cancer Institute NSW and University of Sydney

Optimal care pathways have been compiled for the care of people with lung cancer to support consistent evidence-based care, from prevention and early detection through to end-of-life care. However, population based studies of cancer care pathways are often limited by data that only covers parts of the care pathway, such as care during a hospital admission or in an emergency department. A substantial part of cancer care is now delivered in the primary care or outpatient setting, and the limitation of data in these non-admitted settings hinders the understanding of cancer care pathways.

This project seeks to investigate the quality of diagnostic and treatment pathways for specific aspects of lung cancer care, describe the care pathway, and compare current practice with the optimal care pathway for people with lung cancer. Data linkage affords the opportunity to overcome some of the deficiencies in available data for this investigation. The 45 and Up Study, in particular, through its linkage to data from the Medicare Benefits Schedule and Pharmaceutical Benefits Scheme, enables an assessment of care delivered in primary and community settings. The CHeReL linked records from the 45 and Up Study to the NSW Central Cancer Registry to form the study cohort, and then to the Clinical Cancer Registry, the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection; and the NSW Registry of Births Deaths and Marriages and ABS Mortality Data.

Lung cancer is a priority cancer in the NSW Cancer Plan 2016-2020. Findings from this project should provide a reference point and suggest potential barriers to optimal care that can inform policy and practice around lung cancer care pathways in NSW. Project findings will also potentially contribute important knowledge for future research on health service use in the lung cancer population in NSW.

Back to top

Bleeding, transfusion and obstetric outcomes Associate Professor Christine Roberts, University of Sydney

Postpartum haemorrhage and obstetric transfusions are increasing in NSW, raising questions about how women at risk of haemorrhage or transfusion are

treated, and post-transfusion outcomes. The Patient Blood Management Obstetric and Maternity guidelines make important recommendations about place of birth for women at risk of haemorrhage; however current practices about risk appropriate place of birth, in maternity services capable of providing the appropriate level of care, have not been examined. There is also a lack of information about functional status post transfusion for both mother and baby, and long term reproductive outcomes. Therefore this study proposes four projects to investigate bleeding, transfusion and obstetric outcomes.

The study will examine the place of birth for women with a history of postpartum haemorrhage or pre-existing haematological disorders and women born overseas; examine breastfeeding rates post haemorrhage/transfusion; and investigate subsequent pregnancy and the effects of pre-pregnancy transfusions on the likelihood of and impact on pregnancy and birth outcomes. The study uses the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets linked by the CHeReL used in this study were the NSW Admitted Patient Data Collection; the NSW Register of Births Deaths and Marriages birth and death registrations; the Register of Congenital Conditions; the NSW Perinatal Data Collection; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews, the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Findings from this study will enable determination of long term outcomes following transfusion before and during pregnancy, and will feed into health service planning for provision of resources appropriate to maternal risk of transfusion.

Back to top

45 and Up Study Cohort Management Linkage Project Ms Margo Barr, Sax Institute

The Sax Institute's 45 and Up Study, the largest cohort study ever conducted in Australia, is designed to help determine the community's future health requirements and give government reliable evidence to underpin sustainable policy. Over 267,000 NSW residents 45 years and over were recruited to the 45 and Up Study and have provided information on their health, lifestyle and demographic characteristics, as well as consent to be contacted for further research and to link this data with other administrative data collections.

Ongoing follow-up of any longitudinal study is challenging particularly as the cohort ages and more serious disease and deaths occur. Therefore for ongoing cohort management of the 45 and Up Study cohort, information has been included in the CHeReL Master Linkage Key (MLK) and linked to other health records. Linkage of the following datasets was facilitated by the CHeReL: Death data (NSW Registry of Births Deaths and Marriages death registrations and Cause of Death Unit Record File); Hospitalisation data (NSW Admitted Patient Data Collection); and Cancer notifications and deaths (NSW Central Cancer Registry).

The aim of the 45 and Up Study Cohort Management Project is to link the 45 and Up Study cohort to death data, hospitalisation data and cancer notifications to identify individuals who should not be followed up, to report on follow up non-response, and to validate questionnaire results. The expected benefits from the ongoing linkage to the death data, hospitalisation data and cancer notification datasets, as close to real time as possible, will improve cohort management (deaths and understanding nonresponse) and the quality of the data overall (by comparing questionnaire responses with administrative data).

Back to top

Emerging issues in obstetric care Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

Changing risk profiles of mothers (increasing age and chronic diseases) and their babies (increasing infant size, twins, preterm infants), differences in access, obstetric practices and the availability of maternity care may have significant impact on maternal and infant health outcomes. Current and emerging issues that require investigation include rising trends in elective deliveries (planned pre-labour caesarean section or induction of labour), increasing trend in births before the due date, outcomes of variation in maternity practice, recurrence and impact of obstetric interventions on current and future pregnancy outcomes, and the risk of recurrence of adverse pregnancy outcomes. There is also limited information on the implications of these interventions on long-term child health and development and future pregnancies.

The seven studies proposed within this project will investigate maternal and child outcomes associated with hypertensive disorders of pregnancy; changing patterns of gestational age distribution; maternal outcomes for pregnancies of 20-24 weeks duration; maternal and neonatal outcomes for women with previous pregnancy complications or of advanced maternal age; the impact of inter-pregnancy interval on subsequent pregnancy outcomes following a 2nd trimester loss; and outcomes of abdominal surgery during pregnancy. The burden of disease, trends and predictors, and risk of adverse pregnancy outcomes, subsequent maternal health and infant and child outcomes will be assessed for each project.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets used in this study were the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Findings from the studies will provide information to inform clinical decision making, improving the quality and safety of maternity services and informing maternity care policy and practice.

Back to top

Are 45 and Up Study participants with cancer representative of all people aged 45 years and over with cancer? Professor Jane Young, Cancer Institute NSW and University of Sydney

One of the major limitations of population-based studies of cancer care pathways using administrative data is that readily accessible data only cover parts of the care pathway that are in hospital on an admitted basis or in the emergency department.

The 45 and Up Study is a NSW population-based cohort study that aims to improve knowledge of ageing in order to better manage and prevent illness. Participants of the 45 And Up Study have consented to have their Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data, as well as hospital and other health data, linked and used for health research. Through data linkage, the 45 and Up Study enables a comprehensive assessment of cancer care in primary, community and hospital settings. However as is common with large-scale cohort studies, the 45 and Up Study cohort is not representative of the population from which it was drawn.

In order to understand the magnitude and direction of any biases introduced by using the 45 and Up Study to investigate health services use for cancer care, this project will assess the representativeness of the NSW cancer population aged 45 years and older and will investigate methods to adjust for any differences. Specifically the project aims to compare demographic and cancer case information, and hospital use characteristics in the year prior and two years after a diagnosis of lung or colorectal cancer, for those with cancer in the 45 and Up Study compared to the NSW cancer population. The CHeReL linked all participants in the 45 and Up Study to the NSW Central Cancer Registry, and then linked these records to the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection; the NSW Clinical Cancer Registry and the NSW Registry of Births Deaths and Marriages and ABS Mortality Data.

Findings will determine the extent to which people in the 45 and Up Study diagnosed with cancer are representative of the NSW cancer population. The representativeness of the 45 and Up Study cohort has implications for its use in informing policy and practice around cancer care pathways in NSW.

Back to top

Detecting fatal and non-fatal suicide clusters Dr Matthew Spittal, Centre for Mental Health,

Melbourne School of Population and Global Health, University of Melbourne

Suicidal behaviour is a major health problem, especially among young people. A suicide cluster can be defined as a group of suicides or attempted suicides that occur closer together in time and space than would normally be expected on the basis of statistical prediction or community expectation. Relatively little research has been undertaken into suicide clusters, and the underlying mechanisms are not clear, however it has been proposed that they may be due to a process of 'contagion', whereby one person's suicidal behaviour influences another person's, sometimes with fatal consequences.

This record linkage study combined individual-level data on suicide attempts with individual-level data on completed suicides. The cohort comprised individuals admitted to hospital for deliberate self-harm or who died as a result of deliberate self-harm. This cohort was linked by the CHeReL to the NSW Admitted Patient Data Collection, NSW Registry of Births Deaths and Marriages death registrations and Cause of Death Unit Record File. After extracting all participants hospital admission and death records investigators attempted to: identify suicide clusters (including completed suicides and suicide attempts); identify factors which increase the likelihood of given completed suicides and suicide attempts being part of a cluster; and use this information to construct and assess a risk calculator that can be used prospectively to estimate the probability of a given suicidal event.

This study considers completed and attempted suicide in tandem, which has not been done before, and seeks to identify event-level, individual-level and area-level factors that predict the occurrence of a cluster. Whilst community resources for responding to suicide clusters are useful, one of the main barriers for their uptake is uncertainty about when a cluster exists. This study aims to provide better information than currently exists for identifying emerging suicide clusters, defined in terms of both completed suicides and attempted suicides.

Back to top

Characteristics of long term opioid use in the 45 and Up Study Professor Fiona Blyth, The Sax Institute

Prescription opioid medications are widely used in cancer pain and acute non cancer pain management. Recently a trend in increased use of opioids for chronic non-cancer pain has been observed; however significant concern surrounds the efficacy and adverse event profile, as there is no evidence of efficacy for long term treatment of chronic non cancer pain.

It is important to understand the patterns of use and demographic and health characteristics of those using prescription opioid medication for chronic non-cancer pain. Therefore, using participants from the 45 and Up Study, this project aims to examine the relationship between the use of prescribed opioid

medication and demographic, lifestyle, health, social and other factors; and investigate the usage pattern of long term opioid therapy for chronic non-cancer pain.

Using a retrospective cohort design participants were selected from the 45 and Up Study linked to data from the Medicare Benefits Schedule and the Pharmaceutical Benefits Scheme. The CHeReL linked these records to the NSW Admitted Patient Data Collection and the NSW Central Cancer Registry. This linkage makes it possible to identify the subgroup of people receiving ongoing opioid treatment for cancer pain and the subgroup receiving treatment for other reasons. Opioid usage patterns will be used to compare characteristics of opioid users versus non users by duration of use, drug category, average dosage and total morphine equivalent dose.

Results will help to better describe the characteristics of people prescribed opioid therapy for chronic non-cancer pain and will inform the decision making process and policy around opioid therapy for this use.

Back to top

Emerging issues in obstetric transfusion Dr Jane Ford, Kolling Institute

While obstetric transfusion is a potentially life-saving treatment, there is little evidence to guide practice in terms of identifying the patients that will benefit, the optimal timing and the amount of blood transfused. Release of the 2015 national Patient Blood Management Obstetric and Maternity Guidelines has provided an opportunity to explore obstetric transfusion practices pre and post-guideline. This project aims to investigate emerging issues in obstetric transfusion including the association between volume of blood transfused and outcomes; transfusion rates following trial of labour after previous caesarean compared to elective repeat caesarean; and antenatal admissions for administration of gamma globulin. For each issue the project aims to describe the use of specified interventions and clinical practices in the NSW maternity population, and to assess the risk of adverse maternal, pregnancy and child outcomes.

Record linkage provides the opportunity to investigate these issues in a large population cohort. To facilitate the study the CHeReL linked records from the NSW Perinatal Data Collection, the NSW Admitted Patient Data Collection, the NSW RBDM birth registrations, the ABS Mortality data and the ABS Perinatal Mortality Data, the NSW Perinatal Death Reviews, the NSW Neonatal Intensive Care Unit Study data, the Red Cell Utilisation data on blood banks and pathology (collected as part of the Blood Watch program), and blood service data from the Australian Red Cross Blood Service. The study findings will provide valuable evidence to inform clinical practice and reduce clinical variation, ultimately improving maternal and child health outcomes.

Back to top

Hospitalised injury in NSW: a geographical comparison Associate Professor Rebecca Mitchell, Australian Institute of Health Innovation, Macquarie University

Rural residents are known to experience higher rates of injury related mortality and morbidity compared to their urban counterparts, with hospitalised injury rates for rural residents about 1.4 times higher than urban residents. In terms of work-related injuries, the agricultural industry has one of the highest rates of injury of all Australian industries.

Previous analyses of hospitalised injury comparing rural and urban residents did not use linked hospitalisation and mortality collections which has limited the ability to examine important measures such as hospital readmissions and mortality post hospital discharge. The impact of individual co-morbidities on patient outcomes, and the cost of hospital treatment for injuries, has also been limited.

This project aimed to examine injury hospitalisations in NSW and compare the characteristics of injury requiring hospitalisation among rural and urban residents in NSW. Specifically the project described the number, incidence, characteristics and costs of injury related hospitalisations in rural and urban residents; compared trends over time; examined patient outcomes such as length of stay, unscheduled readmission to hospital, and 30 day mortality for different injuries and their causative mechanisms; and investigated the number and characteristics of work related agricultural hospitalised injuries in NSW. To facilitate this study the CHeReL linked records from the NSW Admitted Patient Data Collection, the NSW Births Deaths and Marriages death registrations, and the ABS Mortality data.

Findings from this project will feed into targeted injury prevention initiatives that meet the specific needs of urban and rural residents. In particular identification of the specific factors associated with work-related hospitalised injuries of rural residents will feed into the development of injury prevention measures for this sector.

Back to top

Long-term psychiatric and mental health effects of concussive head injury among children and adolescents in NSW: An epidemiological study using data-linkage Dr Mary Lam, The University of Sydney

Concussion is one of the most common problems presenting to the emergency department, with over 300,000 presentations annually in Australia and increasing. Childhood concussion may have significant neurological and

psychosocial effects, and more severe concussion with loss of consciousness may have long term sequelae that can take months to return to normal function. There is limited information on the persistent ongoing effects post-concussion, and whilst physical functioning may return to normal, there is still limited evidence surrounding the long term psychiatric and mental health effects. Moreover most of the evidence to date has investigated sports related injuries; consequently there is a need to investigate sports and non-sports injuries, and multiple concussions between both, on a population basis.

This project was designed to investigate two key aims; firstly to determine incidence rates of multiple sports and non-sports concussions and calculate the risk ratio of multiple concussions from different activities; and secondly, to investigate the long term effects of single or multiple concussions on the psychiatric and mental health of young people. The project was also designed to be a feasibility study for a larger program of work, including the development of a Child and Adolescent Mild Traumatic Brain Injury Registry. The intent of this component of the project was to determine the quality and depth of currently available information and identify the additional data that are not available in existing collections. For this project, the CHeReL linked records from the NSW Admitted Patient Data Collection, the NSW Emergency Department Data Collection, the NSW Mental Health Ambulatory Data Collection, death registrations from the NSW Registry of Births Deaths and Marriages, and the Cause of Death Unit Record File.

By determining the magnitude of this health problem and documenting valuable information on the effects of single and multiple episodes of concussion on psychiatric and mental health, this study will make a valuable contribution to the literature. Findings from the study will be used to design injury prevention programs to reduce risk of injury and reduce subsequent repetitive concussions that may cause more serious damage.

Back to top

The HIV Prevention revolution: Using the molecular epidemiology of HIV transmission in NSW to inform the Public Health Response to HIV prevention Professor Anthony Kelleher, The Kirby Institute

The NSW Ministry of Health has set a target to virtually eliminate HIV in NSW by 2020. A state-wide HIV genotype database has been established to define past trends in HIV subtypes, monitor for emerging drug resistance and understand factors relating to transmission of new infections. The addition of clinical and epidemiological data will greatly enhance the utility of this data base.

To facilitate this project the CHeReL linked data from the three reference laboratories in NSW which perform HIV Genotypic Antiretroviral Resistance Testing (GART), to the NSW HIV administrative data set with enhanced

surveillance data. The establishment of this data set will enable the ascertainment of the proportion of transmissions arising from early infections, where HIV viral load is high; investigations of the characteristics of transmission networks in NSW; and will identify changes in drug resistance profiles and subtype diversity in NSW.

This knowledge will provide a better understanding of the contribution of acute infections to new transmissions in the NSW epidemic and will help to focus the emphasis of various strategies to reduce HIV transmission, which is an essential component of the HIV prevention response.

Back to top

Unwarranted clinical variation following hospitalised injury in young people in NSW: Informing trauma and healthcare practices Associate Professor Rebecca Mitchell, Australian Institute of Health Innovation, Macquarie University

Hospital-acquired medical complications following injury or trauma, such as respiratory infections, wound and urinary tract infections, and air or fat embolus, are known to negatively impact on patient outcomes in terms of length of stay, unscheduled readmission to hospital following discharge, cost of treatment or 30 day mortality. However the extent to which medical complications affect young people who are hospitalised in NSW public hospitals for injury is unknown. The common risk factors for complications in young people hospitalised for injury are also poorly understood.

Using a retrospective epidemiological study design this project aimed to examine patient and hospital outcomes related to the hospital treatment of injuries in young people aged 25 years or less. In particular, the project aimed to describe the number, type and cost of medical complications; identify patient risk factors for medical complications by type of complication, injury or medical procedure; and examine indicators of unwarranted clinical variation between public hospitals. The CHeReL linked records from the NSW Admitted Patient Data Collection, the NSW Emergency Department Data Collection, death registrations from the NSW Registry of Births Deaths and Marriages, and the ABS Mortality data.

Findings from this project will feed into health care improvement strategies and interventions to prevent the complications most common in young people experiencing injury and trauma. There will also be opportunities to inform clinical guidelines, policies and procedures for management of injury and trauma in young people admitted to hospital for these conditions.

Back to top

Living with acute coronary syndrome: what happens to people in the early years after discharge from hospital with a coronary event in Australia Associate Professor Julie Redfern, The George Institute for Global Health.

In May 2012, 478 hospitals across Australia and New Zealand participated in an audit – 'SNAPSHOT' - to examine the current management of Acute Coronary Syndrome (ACS). The study revealed that only one quarter of people admitted with ACS received optimal in-hospital preventive care. To examine the post-discharge care of people with ACS and inform future clinical policy and practice the Australian cohort were contacted 18 months later to determine health outcomes, medication use, health service utilisation and costs associated with living with ACS.

The current project sought to supplement the information collected in the initial and follow up studies, with additional information from the Medicare Benefits Schedule (MBS), the Pharmaceutical Benefits Scheme (PBS), health services data and mortality data nationally. The aim was to obtain comprehensive information on medical services accessed and whether evidence based care was delivered, and the impact of receiving – or not- evidence based care on further cardiovascular events and hospital readmissions. The CHeReL linked the cohort to the NSW Admitted Patient Data Collection and the NSW Emergency Department Data Collection, the ACT Admitted Patient Care data and the ACT Emergency Department Information System, and provided these records to the Australian Institute of Health and Welfare for linkage to the MBS and PBS data.

SNAPSHOT is the leading contemporary research describing and informing heart disease care in Australia and New Zealand. Ultimately results from the study will be used to pursue service redesign and policy development for the management of heart disease.

Back to top

Variations in practice in the provision of maternal care Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

Variation in clinical practice is reported in many medical disciplines and reducing unwarranted variation is important where it influences health outcomes and costs, and provision of appropriate patient-focused care. To date, comparison of obstetric variation has largely been limited to caesarean section rates. Comparisons of hospital caesarean rates amongst nulliparous women with a singleton term birth has often been used but is of limited value for generalising results to the entire maternity population. A risk based approach using

classification into groups according to pregnancy characteristics allows a more meaningful comparison amongst hospitals by eliminating potential confounding effects of some characteristics, but it does not take into account other maternal factors that could influence variation.

This series of studies will explore variation in hospital obstetric intervention rates among clinically homogenous groups; determine to what extent variation can be explained by casemix, labour and delivery, and hospital factors; and examine the association between hospital intervention rates, and maternal and neonatal outcomes. In addition to Caesarean section rates, the interventions and outcomes of interest include rates of induction of labour and episiotomy. Secondary child and maternal health outcomes will also be examined.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets used in this study were the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Quantifying divergent hospital intervention rates after adjustment for maternal and pregnancy characteristics (case-mix) is important for determining the role that differences in clinical practice play in practice variation at a hospital level. Identification of demonstrably achievable obstetric intervention rates may help prioritise interventions to enhance maternity care.

Back to top

Investigating services provided in the residential care environment for dementia (INSPIRED NSW) Professor Maria Crotty, Flinders University

Dementia is not a part of normal ageing, and it is the single leading cause of disability burden for people aged 65 years and over. Dementia has now been recognised as the ninth National Health Priority Area. Research undertaken by the AIHW in 2011 demonstrated that over half of residents living in Australian aged care facilities had a recorded diagnosis of dementia at that time.

INSPIRED is a cross-sectional, observational study designed to evaluate the specialised dementia services currently being provided at residential aged care facilities across Australia. Its aim is to determine the cost of, and outcomes from, current residential care service models for people with cognitive impairment and dementia in Australia. Key outcomes of interest include quality of life, quality of care, care preferences, and utilisation of healthcare resources.

In order to expand the breadth and depth of investigations of resource use and health outcomes that were possible from data provided by participants in the INSPIRED study directly, the CHeReL linked records for the NSW participants of

the study to the NSW Admitted Patient Data Collection and the NSW Emergency Department Data Collection. Additional linkages to the Medicare Benefits Schedule and the Pharmaceutical Benefits Scheme are also planned.

These data will contribute to a detailed analysis of the outcomes achieved under different service models nationally, and their alignment with the stated preferences of people with dementia. From this, innovative new models of care and/or funding can be developed to emphasise consumer directed care and more effective and efficient service provision.

Back to top

Care pathways of individuals diverted from local court into the mental health system in New South Wales Associate Professor Kimberlie Dean, Justice Health and Forensic Mental Health Network, University of NSW

Many jurisdictions facilitate diversion of those with mental ill health who come in contact with the criminal justice system from court to mental health services, on the basis that such individuals need mental health treatment rather than criminal sanction. Court diversion or liaison teams operate in these circumstances to assess individuals and make recommendations to the courts with regard to the benefits of diversion for individuals. However little is known about the health care pathways and outcomes for such individuals once diverted and thus the effectiveness of diversion is not established.

Using data from persons assessed by the State-wide Community and Court Liaison Team (SCCLS) within the Justice Health and Forensic Mental Health Network in NSW, this project aimed to describe the care pathways and outcomes of mentally ill people who were diverted from the criminal justice system for summary offences in NSW. The CHeReL linked records from the SCCLS and the Adolescent Health Court Consultation and Liaison Service database to the NSW Bureau of Crime Statistics and Research reoffending database, NSW Admitted Patient Data Collection, the NSW Emergency Department Data Collection, the NSW Mental Health Ambulatory Data Collection, and death registrations from the NSW Registry of Births Deaths and Marriages, and ABS Mortality Data.

This important research provided a unique opportunity to assess the effectiveness of court diversion and to inform recommendations for improvement. It provided a better understanding of the patterns of healthcare pathways and outcomes following diversion and the factors that dictate successful diversion into mental health services from the criminal justice system. The findings will assist in future service development to reduce the amount of time that mentally ill persons spend in custody, thus reducing the effect of detention on their housing, employment, health and social contacts. Improvements in the treatment of those with mental ill health in contact with the

criminal justice system can have the potential to improve the impacts of mentally disordered offenders on the community both in terms of the burden of their ill health and future criminality.

Back to top

PRofiling Immune Suppressed Melanomas (PRISM) Study Associate Professor Angela Webster, University of Sydney

Compared to non-immune suppressed individuals, immunosuppressed people are at increased risk of melanoma. Furthermore, their melanomas are diagnosed at a more advanced stage and survival is markedly poorer. While the immune system is intimately related to melanoma behaviour in the general population, there is extremely limited evidence on the molecular features of melanomas in immunosuppression.

This study seeks to compare the histopathological, immunological and molecular characteristics of melanomas diagnosed in immune supressed and matched non-immune suppressed patients, plus examine the correlation between melanoma phenotype and genotype in immune suppressed compared to non-immune suppressed patients. Tissue samples were obtained from the Melanoma Institute Australia (MIA) biobank, the world's largest biorepository of fresh frozen and formalin fixed paraffin-embedded primary and metastatic melanomas.

To facilitate this nested case control study, the CHeReL linked data from the MIA biobank to the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA), to identify cases with melanoma who were also immunosuppressed due to dialysis or after kidney transplantation. Non-immune suppressed individuals with melanoma from the MIA formed the control group.

Understanding the relationship between immune function and melanoma behaviour is now critically important as we see compelling Phase I trial evidence that monoclonal antibodies can achieve durable responses among 30-50% of patients with advanced melanoma. These agents regulate adaptive immunity, unblocking specific immune responses to melanoma cells. This study seeks to address fundamental gaps in knowledge about the interaction of the immune system with melanoma. The characterisation of what is distinctive about immune suppression-related melanoma promises to benefit both transplant patients and melanoma care more broadly.

Back to top

Exploring unplanned readmission and avoidable admission rates among Aboriginal and non-Aboriginal patients with chronic disease L/Professor Rob Sanson-Fisher, University of Newcastle

Whilst hospital readmission rates are high for many people with chronic disease, Aboriginal people are reported to have significantly higher rates of readmission for chronic respiratory disease, diabetes and cardiovascular disease than non-Aboriginal Australians.

Readmissions place a substantial burden on health systems, and individuals through lost time from home responsibilities and employment. This study is therefore focused on investigating the patterns and predictors of unplanned and potentially preventable readmissions.

Using non-Aboriginal people as a comparison, the aims of this project were to investigate the rates of unplanned hospital readmissions over time, examine the differences in rates of unplanned readmissions for selected chronic diseases, establish the distribution of avoidable readmissions and to quantify the extent to which patient, disease and hospital factors contribute to readmission.

The cohort was formed by selected all persons aged 18 years and over with at least one admission for either cardiovascular disease, cerebrovascular disease, diabetes, chronic respiratory disease or renal diseases, in the NSW Admitted Patient Data Collection, and where Aboriginality was coded 'yes'.
The CHeReL linked records from the NSW APDC, the NSW Emergency Department Data Collection, and the NSW RBDM death data. The CHeReL also randomly selected a matched control from the APDC for each Aboriginal case where Aboriginality was recorded as 'no' across all admissions.

Findings from this project will provide important information for the future development of Aboriginal health services, and the development of strategies to reduce readmission and avoidable hospitalisations.

Back to top

Determinants of health disparities in women with chronic heart failure: An investigation of risk characteristics, hospital admission and health outcomes of older women with chronic heart failure Dr Sungwon Chang, University of Technology

Chronic heart failure (CHF) is a common, deadly and disabling condition that is costly, requiring frequent hospitalisation and ongoing symptom management. Recent studies have suggested sex differences in the underlying aetiology, epidemiology and outcomes of CHF patients. CHF seems to affect women at an older age with greater incidence of co-morbidities, and whilst they have better survival from CHF than men, they have a poorer quality of life with more symptoms and limitations in physical functioning. Despite this, there is evidence that women are often undertreated. Overall CHF in women is poorly understood both in pathophysiological processes, patterns of health service utilisation and models of care development.

The aim of this project is to describe patterns of care and to identify risk characteristics associated with hospital admission and mortality in older women with CHF. Using participants in the 45 and Up Study, the project aimed to examine trends in hospitalisation, health service utilisation and mortality; and describe the socio-demographic, behavioural and lifestyle characteristics predictive of CHF in women aged 45 years and over. A risk prediction model of CHF hospitalisation and mortality, mediated by health service utilisation, will also be developed.

The CHeReL linked records from the 45 and Up Study to the NSW Admitted Patient Data Collection, and the NSW RBDM death data. Records obtained from the 45 and Up Study included Department of Human Services Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data.

Study findings will address two National Research Priorities: Ageing well and ageing productively; and Strengthening Australia's social and economic fabric. Results from the study will be used for health services planning and evaluation to improve the care of women with CHF, and will aid the development of tailored and targeted heath interventions.

Back to top

Chronic disease management plans: Who receives them and do they make a difference to the use of health care services and health outcomes? Dr Rosemary Korda, Australian National University

A General Practitioner Management Plan (GPMP) is developed by a general practitioner (GP) for patients with chronic conditions who require a structured approach to their care. A GPMP enables GPs to plan and coordinate the care of patients with complex conditions requiring ongoing care from a multidisciplinary team. This study aims to compare patterns of health care and health outcomes in those who do and do not have a current GPMP for asthma, heart disease or diabetes.

Using participants from the 45 and Up Study, the project aims to compare patterns of health service use – visits to doctors, hospital admissions and emergency department attendances; compare the costs of doctor and hospital visits; and compare mortality rates in people with and without a GPMP.

Participants were selected from the 45 and Up Study linked to data from the Department of Human Services Medicare Benefits Schedule. The CHeReL linked these records to the NSW Admitted Patient Data Collection; NSW Emergency Department Data Collection; the NSW Registry of Births Deaths and Marriages death registrations and the ABS Mortality Data.

Results will help to demonstrate the benefits arising from use of GPMPs for people with chronic conditions and will inform future policy development for chronic disease management.

Back to top

NSW and ACT Cancer Registry health system performance reporting utilising linked administrative data to examine care, treatment patterns and health outcomes for people with cancer in ACT and NSW Ms Deborah Baker, Cancer Institute NSW

This project sought to establish a linked data set for operational reporting of cancer outcomes in NSW and the ACT. As part of the current and subsequent Cancer Plans for NSW, there is a need to develop and monitor key indicators for cancer control – including operational, program and performance monitoring and evaluation, quality improvement, health services planning and evaluation, and benchmarking against best practice. The complexity of the health system for people with cancer means that people are treated in multiple settings, and their information is collected in numerous administrative data collections, making it difficult to develop a complete picture of the patient's traverse through the health system during and after treatment.

The NSW and ACT Cancer Registries formed the cohort for this program of work. In addition to this, cases with Hepatitis C from the NSW Notifiable Conditions Information Management System and the ACT Communicable Notifiable Diseases Management System, plus all records from Breast Screen NSW and the NSW Pap Test Register, are included in the cohort. The CHeReL linked the cohort cases with the NSW Admitted Patient Collection, NSW Emergency Department Data Collection, NSW RBDM death registrations, NSW Cause of Death Unit Record File, ACT Emergency Department Information System, ACT BDM death registrations, ACT Cause of Death Unit Record File, ACT Admitted Patient Care, and the NSW Retrospective Radiotherapy Data Set. Identifiers were sent to the Australian Institute of Health and Welfare for linkage to the National Death Index. Permission is also in progress for the relevant Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data from the Department of Human Services.

This large complex linked data set will be pivotal to reporting on progress against the NSW Cancer Plan and findings will be used to ensure that cancer care pathways are appropriate and treatment for people with cancer in NSW remains world class.

Back to top

Emerging issues in maternal health Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

Improved care for chronic diseases and delayed childbearing mean that there are increasing numbers of pregnant women with chronic medical conditions. Information on pregnancy and subsequent maternal and child health outcomes associated with these pregnancies is lacking. Many conditions and procedures are rare in pregnant women making them difficult to study, with research limited to case reports or case series. Thus specific management guidelines often do not exist and long term consequences of pregnancy outcomes remain unknown.

This project consists of 11 studies to examine emerging issues in maternal health and investigate pregnancy, maternal and child health outcomes for women who have the following conditions: prosthetic heart valves; organ transplant; intra-hepatic cholestasis of pregnancy; inflammatory bowel diseases; bleeding and blood disorders; breast surgery prior to pregnancy; early onset cardiovascular disease; incisional hernia repair; gynaecological procedures; autoimmune diseases and sleep disorders. For each condition the aims are to assess the burden of disease in the NSW population; examine fertility rates; describe when and how women are delivered; and compare the risk of adverse pregnancy outcomes, maternal health and infant and child outcomes compared to women without the condition.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets used in this study were the Pacific Laboratory Medicine Service (PaLMs); the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection; the NSW Newborn Screening Programme; the NSW Pharmaceutical drugs of addiction system; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

For this study data linkage provides greatly enhanced potential for increasing the understanding of chronic diseases in pregnancy. Findings will feed into the development of clinical management guidelines which will ultimately improve maternal and child outcomes.

Back to top

Social emotional and behavioural functioning in childhood: identification, continuity and predictors Professor Vaughan Carr, University of NSW Research Unit for Schizophrenia epidemiology

Early indicators of behavioural and emotional dysregulation are known to predict later adult achievement and adverse mental health outcomes. However the timing and role of potentially modifiable risk and protective factors operating in early life is poorly understood, and studies assessing the relationships between

variables of interest have largely compared only a few variables and are therefore lacking in complexity.

This study aims to determine the population prevalence and continuity of social, emotional and behavioural problems from early (5 years) to middle childhood (11 years) and their associated risk and protective factors, and to identify risk profiles at age 11 years for specific adult mental health disorders and/or criminal offending based on parental history of these conditions. It will also investigate which factors – if any – moderate the level of risk, and determine the impact of school based delivery of mental health promotion strategies.

Data linkage provides a unique opportunity to examine early childhood exposures to a variety of health and social factors. Using self-reported data from a state-wide survey of mental health and wellbeing of Year 6 students: the 2015 Middle Childhood Survey, and bringing together child, mother and father records for the NSW Child Development Study cohort, the CHeReL linked records from the 2015 Middle Childhood Survey to the NSW Admitted Patient Data Collection, the NSW Perinatal Data Collection, NSW Emergency Department Data Collection, NSW Mental Health Ambulatory Data Collection, NSW Pharmaceutical Drugs of Addiction System, the NSW Mental Health Outcomes and Assessment Toolkit, the NSW RBDM births and death registrations plus the Cause of Death Unit Record File, the Australian Early Development Index, the National Assessment Program Literacy and Numeracy data, the Best Start Kindergarten Assessment, the NSW School Enrolment records and NSW Suspensions and Expulsions data, the Case Management System from the NSW Department of Family and Community Services, and the NSW Bureau of Crime Statistics and Research Re-offending Data Collection.

The study will identify risk and protective factors that influence mental health-related outcomes from early to middle childhood. This will provide critical information for translation into population health strategies for early intervention plus inform the development of policy initiatives and targeted programs for selected children showing early risk for particular adverse outcomes.

Back to top

Emerging issues in child health Dr Natasha Nassar, The Kolling Institute, University of Sydney

A child's health at birth has significant impact on their long-term health and development. Infants born early, or growth restricted, are at greater risk of incomplete brain development and health problems and these may have long-term implications in terms of neurological ability.

The aim of this study is to investigate infant health at birth and its association with long-term health outcomes and educational literacy and numeracy achievements. Five studies will examine health, developmental and educational outcomes for children who are born late preterm/early term; are born with or

without severe neonatal morbidity; are born to mothers with abnormal antenatal screening results in early pregnancy; have metabolic disorders or mildly abnormal screening results; or have congenital anomalies. For each of these conditions the study will assess the burden of disease and trends in NSW; maternal and infant risk factors and characteristics for each condition; health outcomes and service utilisation and associated costs for infants with and without each condition, and the association of each condition with developmental and educational outcomes.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets linked by the CHeReL used in this study were the Pacific Laboratory Medicine Service (PaLMs); the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection; the NSW Newborn Screening Programme; the NSW Pharmaceutical drugs of addiction system; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Findings will quantify the contribution of timing of birth and adverse infant health at birth and poor educational outcomes. This will help to identify mothers and babies at risk and inform preventive measures to improve health and educational outcomes for young Australians.

Back to top

Exploring the relationship between social care, primary & secondary health service use and adverse health outcomes Dr Peter Lewis, Central Coast Local Health District

Integration between health services on the continuum of care can lead to improved health system efficiency and improved health continuity, quality and outcomes for the patient. The 'NSW Integrated Care Strategy' emphasises locally-led models of integrated care, with Local Health Districts (LHDs) partnering with other agencies, with joint governance, shared financial incentives and shared IT systems. The Central Coast LHD is exploring integrated care among social care providers, general practice and LHD services, with an area of focus on older people and the chronically ill.

By investigating patterns of health and community service use, demographic characteristics and factors associated with service use, this project aims to develop a series of predictive models of impending emergency hospital admission, emergency department attendance, residential aged-care admission, or a significant change in health state or death. These indicators of declining health can then be used to develop and evaluate pre-emptive interventions to

prevent unplanned hospital admissions and attendances, declining health status or unexpected death.

Using participants in the 45 and Up Study as the cohort, the CHeReL linked records to the Home and Community Care data for NSW, the NSW Admitted Patient Data Collection, the NSW Emergency Department Data Collection, and the NSW RBDM death data. Department of Human Services Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data, available from the 45 and Up Study, were also obtained.

Findings from this study will contribute to the understanding of health and community services use, and will be used to inform the development of early prevention interventions for people who are identified as being on a declining health trajectory. More broadly findings will contribute to the implementation and evaluation of the NSW Strategic Framework for Integrated Care.

Back to top

Early childhood development and beyond Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

Children's early developmental outcomes are well-known to play a significant role in their long-term education achievements and occupation attainment. Socio-demographic characteristics such as a child's individual characteristics and their home experiences influence early developmental outcomes. Despite the growing body of evidence in this area, there are still substantial gaps in the knowledge base.

This study examines the role of individual, home and socio-demographic factors on child development outcomes, and their links with subsequent academic achievement. Two studies will be undertaken to investigate the association between individual, home and related characteristics and developmental outcomes; and the links between early childhood development and academic outcomes.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets linked by the CHeReL used in this study were the NSW Perinatal Data Collection; the NSW Pharmaceutical drugs of addiction system; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Early childhood sets the foundation for social, physical, emotional, cognitive, and academic development. A healthy start to life ensures children have the foundation and basis for lifelong learning and educational achievement. This project will provide important information about early development among NSW children and will demonstrate links between developmental outcomes and later academic outcomes. Findings may contribute to understanding areas of early development that require greater societal and educational support.

Back to top

Emerging issues in child health Dr Natasha Nassar, The Kolling Institute, University of Sydney

A child's health at birth has significant impact on their long-term health and development. Infants born early, or growth restricted, are at greater risk of incomplete brain development and health problems and these may have long-term implications in terms of neurological ability.

The aim of this study is to investigate infant health at birth and its association with long-term health outcomes and educational literacy and numeracy achievements. Five studies will examine health, developmental and educational outcomes for children who are born late preterm/early term; are born with or without severe neonatal morbidity; are born to mothers with abnormal antenatal screening results in early pregnancy; have metabolic disorders or mildly abnormal screening results; or have congenital anomalies. For each of these conditions the study will assess the burden of disease and trends in NSW; maternal and infant risk factors and characteristics for each condition; health outcomes and service utilisation and associated costs for infants with and without each condition, and the association of each condition with developmental and educational outcomes.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets linked by the CHeReL used in this study were the Pacific Laboratory Medicine Service (PaLMs); the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection; the NSW Newborn Screening Programme; the NSW Pharmaceutical drugs of addiction system; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Findings will quantify the contribution of timing of birth and adverse infant health at birth and poor educational outcomes. This will help to identify mothers and babies at risk and inform preventive measures to improve health and educational outcomes for young Australians.

Back to top

Vasovasostomy and prostate cancer in vasectomised men Associate Professor James Boyd, Department of Health Services, Curtin University

While links between prostate cancer and vasectomy have been found previously, it has been suggested that men who receive vasectomies may receive more medical attention, which may be the true cause of higher diagnosis rates. The overall aim of this study was to determine whether vasectomy reversal has a

protective effect on prostate cancer. Researchers investigated the risk of prostate cancer in those who have had a vasectomy reversal, removing the possible source of methodological bias and gaining a more accurate understanding of the effect.

The CHeReL identified the study cohort of men who had an in-hospital vasectomy or vasovasostomy (between 2001 and 2014) in the NSW Admitted Patient Data Collection (APDC) and linked the cohort data to other records in the APDC as well as data in the NSW Central Cancer Registry, NSW Registry of Births, Deaths and Marriages (Death Registrations), and Cause of Death Unit Record File.

This study will provide a more complete understanding of the relationship between prostate cancer and vasectomy; with the overall aggregate results (i.e. effect size) being used in an international meta-analysis conducted using the same study design in a range of jurisdictions.

Back to top

Perinatal exposures and childhood outcomes Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

This project aims to investigate the long term effects of perinatal exposures on child health and development. Given a significant proportion of brain growth, development, networking and synapse formation occurs during the last six weeks of gestation, these late pregnancy exposures may increase the risk of incomplete brain development and subsequent neuro-cognitive impairments.

The five studies proposed within this project will investigate child health and development outcomes for children exposed to preterm labour rupture of membranes in utero, or exposed preterm labour with and without preterm birth; evaluate low birthweight as an indicator of the quality of maternity care; and will examine outcomes following breech presentation at term by mode of delivery; and outcomes following laser surgery for twin-twin transfusion syndrome. For each study the frequency and trends of each exposure will be described, and child health outcomes, early childhood development and disability, and educational outcomes will be explored.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets used in this study were the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection; the NSW Register of Births Deaths and Marriages birth and death registrations; the NSW Pharmaceutical drugs of addiction system; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

This project provides the opportunity to examine the long term effects of perinatal exposures in a large population cohort. Findings will generate valuable information to inform maternity practice and the development of initiatives to improve child health and education outcomes.

Back to top

Factors relating to cancer incidence, care and outcomes in the 45 and Up Study Associate Professor Karen Canfell, Cancer Research Division, Cancer Council NSW

Large changes to the structure of the Australian population are predicted for the near future such that the number of people aged over 65 will increase by almost 50% in the next 10 years. In terms of health, these changes will carry a significant increase in the social and financial burden to the Australian public and the issue of 'healthy aging' will be a prominent concern. There is a lack of large-scale, prospective data on risk factors for cancer in Australia. Importantly, age is the largest risk factor for most cancer types, with more than half of all cancers diagnosed in NSW occurring in individuals over the age of 65. Thus, the focus on older individuals in the 45 and Up Study cohort was particularly suited to examining risk factors for cancer incidence, care and outcomes.

This study aimed to quantify the association of cancer incidence, mortality, and all-cause mortlaity with known and emerging lifestyle, socio-demographic, and health-related cancer risk factors; and identify factors and issues in cancer care with relation to health services use.

The 45 and Up Study was linked by the CHeReL to the NSW Central Cancer Registry, NSW Register of Births, Deaths and Marriages death registrations, Cause of Death Unit Record File, NSW Admitted Patient Data Collection, and NSW Emergency Department Data Collection., Medicare Benefits Schedule and Pharmaceutical Benefits Scheme was linked by the Sax Insitute through the 45 and Up Study.

The 45 and Up Study provided a unique opportunity for expanding on what is known in Australia about risk factors, health outcomes, and health services use in relation to cancer. Findings from this study could be used to guide the development of health policy in Australia to address cancer risk factors.

Back to top

Incidence and burden of childhood injury in Australia Associate Professor Rebecca Mitchell, Australian Institute of Health Innovation, Macquarie University

The total burden and causes of paediatric injury in Australia by injury severity 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, and these factors need to be examined so they can be taken into account in the provision and coordination of trauma care for injured children. Accordingly, this study aimed to estimate and describe the burden of hospitalised childhood injury and related follow-up care in Australia and determine the severity of the injuries experienced and factors influencing survival.

In order to fulfil this objective, the study aimed to determine the distribution of injury severity for hospitalised childhood injury in Australia; describe the number, demographic characteristics, injury characteristics and outcomes of children who were hospitalised as a result of injury in Australia; identify any temporal changes in the characteristics or severity of childhood injury resulting in hospitalisation; and determine the type of hospitals where children with severe injury are treated and the incidence of transfer to other hospitals for higher level of care.

Linked personal identifiers from the cohort were extracted by the CHeReL from the NSW Admitted Patient Data Collection and ACT Admitted Patient Collection to facilitate linkage by the AIHW. Data from the selected cohort was mapped to the format used by the National Hospital Morbidity Database and then linked to the National Death Index by AIHW in order to identify any deaths that occurred after the child was released from hospital.

This research will better inform injury prevention strategies, research priorities, trauma system design, health service planning and resource needs for injured children.

Back to top

Population based risk factors for fracture Professor Emily Banks, Australian National University

Fractures are a significant source of morbidity, mortality, disability and institutionalisation in the community, and are becoming an increasing health problem with the ageing population. A number of potentially modifiable risk factors have been identified and current areas of research interest include hormonal factors, pharmacological agents and sun exposure.

Therefore this study aims to use the 45 and Up Study to investigate potentially modifiable factors for fracture risk, with a particular focus on sun exposure and related factors; bisphosphonates and related medications; and progestogen-only contraceptives. The CHeReL linked records from the 45 and Up Study to the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection, the NSW Registry of Births Deaths and Marriages death registrations; and the NSW Central Cancer Registry. Records from the 45 and Up Study were linked to records from the Department of Human Services Pharmaceutical Benefits Scheme by the Sax Institute.

The identification of potentially modifiable risk factors for fractures in the Australian context will inform preventive policy, with particular reference to the ageing population.

Back to top

Bleeding, transfusion and obstetric outcomes. Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

Postpartum haemorrhage and obstetric transfusions are increasing in NSW, raising questions about how women at risk of haemorrhage or transfusion are treated, and post-transfusion outcomes. The Patient Blood Management Obstetric and Maternity guidelines make important recommendations about place of birth for women at risk of haemorrhage; however current practices about risk appropriate place of birth, in maternity services capable of providing the appropriate level of care, have not been examined. There is also a lack of information about functional status post transfusion for both mother and baby, and long term reproductive outcomes. Therefore this study proposes four projects to investigate bleeding, transfusion and obstetric outcomes.

The study will examine the place of birth for women with a history of postpartum haemorrhage or pre-existing haematological disorders and women born overseas; examine breastfeeding rates post haemorrhage/transfusion; and investigate subsequent pregnancy and the effects of pre-pregnancy transfusions on the likelihood of and impact on pregnancy and birth outcomes. The study uses the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets linked by the CHeReL used in this study were the NSW Admitted Patient Data Collection; the NSW Register of Births Deaths and Marriages birth and death registrations; the Register of Congenital Conditions; the NSW Perinatal Data Collection; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews, the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Findings from this study will enable determination of long term outcomes following transfusion before and during pregnancy, and will feed into health service planning for provision of resources appropriate to maternal risk of transfusion.

Back to top

Obesity and Hospitalisation Professor Emily Banks, Australian National University

The majority of Australian adults are overweight or obese and the prevalence continues to increase, with high body mass index (BMI) estimated to be responsible for 7.5% of the burden of disease in Australia. In addition, Indigenous adults have twice the prevalence of obesity to the general

population. Despite this there is very limited information on the effect of overweight and obesity on the risk of hospital admission.

Using participants from the 45 and Up Study this project aims to identify targets for interventions to reduce hospitalisation and thereby some adverse health outcomes arising from overweight and obesity, in Indigenous and non-Indigenous adults. Specific aims are to investigate the risk and costs of hospitalisation in those with high BMI; determine which diagnoses, adverse events, types of hospital stays and outcomes are affected by increased BMI; and investigate factors that increase or reduce the likelihood of obesity-related adverse outcomes. To facilitate the project the CHeReL linked records from the 45 and Up Study to the NSW Admitted Patient's Data Collection, the NSW Registry of Births Deaths and Marriages death registrations, and the NSW Central Cancer Registry.

Findings from the study will help to identify targets for interventions to reduce hospitalisation in people who are overweight and obese.

Back to top

Linkage of the Australian Childhood Immunisation Register (ACIR) and State-Based Registers to Evaluate and Inform Australia's Immunisation Program Dr Heather Gidding, University of New South Wales, in collaboration with researchers from the Telethon Kids Institute led by Dr Hannah Moore

To optimise the health and cost benefits of Australia's immunisation program, accurate data are required about how well the program is performing. Currently, this information is derived from stand-alone databases such as the Australian Childhood Immunisation Register (ACIR) and compared to separate databases about the occurrence of vaccine preventable diseases. While analysing these datasets in isolation is useful, their linkage would allow more accurate and detailed studies on the relationship between vaccination uptake, timeliness of vaccination, and development of disease, particularly in specific risk populations who may experience a higher burden of infection.

This project aims to:

1) Measure vaccine uptake and timeliness of childhood vaccinations at a population-level, particularly in at-risk populations (such as Aboriginal children and other groups targeted by special vaccination programs), and identify factors associated with vaccine uptake and timeliness.

2) Calculate the direct and indirect effectiveness of currently available childhood vaccinations at a population level and in at-risk populations, identify

factors associated with vaccine effectiveness, and compare estimates over time and between NSW and WA.

3) Inform the development of Australia's data linkage infrastructure through a Proof of Concept Collaboration with the Population Health Research Network (PHRN).

This is a retrospective population-based cohort study of live births from 1996 to 2012, recorded on the Registry of Births in either WA or NSW. In NSW this cohort was linked by the CHeReL to the NSW Perinatal Data Collection, NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection and NSW Notifiable Conditions Information Management System. AIHW linked the cohort to the Australian Childhood Immunisation Register and the National Death Index.

Back to top

Management and outcomes of multi-fetal pregnancies Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

Multi-fetal pregnancies have higher rates of infant morbidity and mortality and maternal morbidity. Infants are more likely to be born prematurely and suffer intra-uterine growth restriction, and they use a disproportionate amount of maternity and neonatal services. Optimising decision-making for

multi-birth pregnancies has the potential to reduce morbidity for infants and mothers and to reduce the burden on health services. However there is limited evidence of sufficient robustness to guide decisions about delivery at or near term.

The aim of this study is to examined the distribution, trends and effects of timing and mode of delivery of multi-fetal pregnancies on birth outcomes, childhood outcomes, antepartum, intrapartum and postpartum maternal morbidity, and longer term maternal morbidity. Outcomes will be compared to single birth pregnancies.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets used in this study were the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Data linkage provides the opportunity to examine even rare outcomes such as perinatal death in this population. Findings from the studies will provide

information to inform clinical decision making, improve the quality and safety of maternity services and inform maternity care policy and practice.

Back to top

An integrated national assessment of cervical cancer prevention, incidence and survival for Australian Aboriginal and Torres Strait Islander women
Professor John Condon, Menzies School of Health Research

Cervical cancer is one of the most preventable cancers but despite this it has a much greater impact on Indigenous than other Australian women. Although national data are not available, local reports indicate that Indigenous women have lower participation in screening, are diagnosed later with more advanced disease, and have higher incidence, higher mortality and lower survival rates.

Australia has had a nationally coordinated approach to cervical screening (the National Cervical Screening Program) since the early 1990s, including state based Pap Test Registers that provide data to monitor and evaluate cervical screening. However, the registers do not record Indigenous status because this information is not on the pathology forms sent to the registers. Consequently, no national data on cervical screening participation or follow up after abnormal results for Indigenous women are available.

By linking the state based Pap Test Registers to hospital attendance data, which has a known high level of accuracy for recording of Indigenous status, a high proportion of records on the Pap Test Registers can have Indigenous status appended. The CHeReL linked hospital attendance data and data from the Cancer Registries for NSW and the ACT to the NSW Pap Test Registry data, and provided this to the national data set.

This study provides the opportunity to assess the effectiveness of the National Cervical Screening Program for Indigenous women for the first time since the co-ordinated screening program began in 1991. The data will be used to investigate participation in screening, prevalence of abnormal results and timeliness of investigation for abnormalities, time trends, and outcomes such as survival. The influence of factors such as remoteness of residence, socioeconomic disadvantage, age and co-morbidities can also be studied. This information can be used to establish culturally appropriate programs to improve screening for Indigenous women to prevent cervical cancer.

Back to top

Defining the burden and long-term outcomes of central nervous system (CNS) infections in Australian

children Dr Gulam Khandaker, The University of Sydney and Children's Hospital Westmead

Central nervous system (CNS) infections including meningitis, encephalitis, and myelitis are important causes of mortality and morbidity in children. The pathogens responsible are most commonly bacteria or viruses, but may also be fungi or parasites. The burden and aetiology of CNS infections in children vary over time, by geographic region, age, co-morbidities and vaccination policies. There are limited Australian data on either the epidemiology of CNS infections in Australian children or their long-term outcomes, but selected publications from North America and Europe report declining mortality. However this brings with it the likelihood of more childhood survivors living with long term morbidity and disability.

This study aimed to determine the incidence, aetiology and mortality of children aged less than 15 years hospitalised with CNS infections over the preceding decade, and to estimate long term morbidity as shown by health service use, long term disability score, neurodevelopment, mental and behavioural outcomes. Risk factors for admission and death were also studied.

Using a frequency-matched population based case control design, children admitted to NSW hospitals with a CNS infection were compared with a randomly selected matched control extracted from the Perinatal Data Collection. For this study, the CHeReL linked the NSW Admitted Patient Data Collection to the NSW Perinatal Data Collection and ABS mortality records, and selected the matched controls.

Results from this study facilitated the development of evidence-based public health policy and clinical guidelines in order to prioritise prevention strategies such as vaccination campaigns, service provision during and after admission, and improve clinical practice.

Back to top

Home to Outcomes - a data-linkage study of the stroke journey (H2O Study) Associate Professor John Worthington, Ingham Institute for Applied Medical Research, University of NSW

Stroke is a leading cause of disability in Australia. The Home to Outcomes (H2O) study aimed to provide a large scale and representative view of the epidemiology, management and outcomes of stroke across NSW, following the acute stroke patient journey from home to outcomes assessed at one year and beyond.

The H2O study estimated the epidemiology of stroke in NSW; determined short and long term outcomes such as all-cause and cause-specific mortality, hospital

readmissions and functional outcomes; and assessed innovations in health service delivery for improving stroke outcomes.

In providing the opportunity to examine the whole stroke patient journey, patients identified with a diagnosis or comorbidity of stroke in the NSW APDC, ACT Admitted Patient Care (APC), COD URF, NSW SNAP, and Ambulance NSW dataset were linked by the CHeReL to other records in the NSW APDC, NSW EDDC, NSW Ambulance, NSW RBDM death registrations, COD URF, NSW AN-SNAP, ACT APC and ACT Emergency Department Information System (EDIS).

The H2O study is likely to provide new evidence on what determines good outcomes, but also in auditing current services and practices, identifies where the practical application of evidence requires improvement.

Back to top

EXTEND45 - EXamining ouTcomEs in chroNic Disease in the 45 and Up Study Dr Meg Jardine, The George Institute for Global Health

Over half of people aged over 45 years have at least one chronic disease, many of which pose significant burden in terms of morbidity, mortality and health costs. EXTEND45 will explore two chronic conditions, diabetes and chronic kidney disease (CKD) and their comorbidities. These conditions usually develop slowly therefore they are less easily studied in hospital datasets. In addition hospital data sets do not provide a full population perspective on the true burden of these conditions, as much of the management occurs in community settings.

To counter this, 45 and Up Study data will be used to investigate these conditions at a population level. For the first time, diagnostic results held by private pathology companies will be obtained for 45 and Up Study participants through data linkage. Inclusion of pathology data will identify participants with early disease and will assess achievement of clinical targets.

This project aims to establish a community chronic disease cohort using diabetes and CKD as an example and demonstrate the feasibility of linkage to private pathology datasets. This will enable calculation of the population prevalence of these conditions, and examination of the associations between demographic, socioeconomic and risk factors. Concurrent linkage to administrative datasets will facilitate assessment of health service use, the impact of comorbidities, and complications.

The CHeReL linked 45 and Up data to pathology data as well as data from the NSW Admitted Patient Data Collection, NSW Mortality data (NSW Registry of Births, Deaths and Marriages and Australian Bureau of Statistics mortality data) and the Australian and New Zealand Dialysis and Transplant Registry using probabilistic linkage. 45 and Up data were linked deterministically to Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) by the Department of Human Services.

Not only will this project be able to describe more accurately the burden of these conditions at a population level, but it presents a unique opportunity to test the feasibility of linkage with pathology data for the first time, offering opportunities to study other conditions in a similar manner.

Back to top

Physical and psychosocial outcomes in adult cancer survivors Prof Andrew Lloyd, NSW Cancer Survivors Centre and Dr Kate Webber, Lowy Cancer Research Centre

One in two men and one in three women will be diagnosed with cancer by the age of 85 years, and with the increasingly ageing population new cancer diagnoses will continue to increase. Simultaneously, with improved detection and treatment, survival from cancer is improving. Cancer survivors are therefore a large and growing group in the community, and they face many challenges beyond their treatment phase. Along with the risk of recurrence or progression of their cancer, cancer survivors have increased risk of ongoing self-reported co-morbidity and behaviour change, and higher rates of non-cancer mortality. There are few studies comparing the health care utilisation and financial burden of cancer survivors with the non-cancer population, and so the impact of increasing cancer survivorship at the individual and system level is yet to be investigated fully in the Australian setting.

This project seeks to investigate the impact of a cancer diagnosis on the lifestyle behaviours, physical and psychosocial health outcomes and health burden, and financial burden in cancer survivors.

Using a case control design, the study uses the 45 and Up Study cohort to identify cancer survivors and compare their outcomes with matched controls. Records from the CHeReL Master Linkage Key were extracted for cases and controls from the NSW Cancer Registry, NSW Admitted Patient Data Collection, Emergency Department Data Collection, NSW Pap Test Register, and deaths from the NSW Registry of Births Deaths and Marriages and the Australian Bureau of Statistics. The 45 and Up Study also includes records from the Pharmaceutical Benefits Scheme and the Medicare Benefits Schedule which will be used to investigate health burden and service utilisation. Results from this project will provide a better understanding of the current and future health and service needs of cancer survivors.

Back to top

Variations in practice in the provision of maternal care Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

Variation in clinical practice is reported in many medical disciplines and reducing unwarranted variation is important where it influences health outcomes and costs, and provision of appropriate patient-focused care. To date, comparison of obstetric variation has largely been limited to caesarean section rates. Comparisons of hospital caesarean rates amongst nulliparous women with a singleton term birth has often been used but is of limited value for generalising results to the entire maternity population. A risk based approach using classification into groups according to pregnancy characteristics allows a more meaningful comparison amongst hospitals by eliminating potential confounding effects of some characteristics, but it does not take into account other maternal factors that could influence variation.

This series of studies will explore variation in hospital obstetric intervention rates among clinically homogenous groups; determine to what extent variation can be explained by casemix, labour and delivery, and hospital factors; and examine the association between hospital intervention rates, and maternal and neonatal outcomes. In addition to Caesarean section rates, the interventions and outcomes of interest include rates of induction of labour and episiotomy. Secondary child and maternal health outcomes will also be examined.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets used in this study were the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Quantifying divergent hospital intervention rates after adjustment for maternal and pregnancy characteristics (case-mix) is important for determining the role that differences in clinical practice play in practice variation at a hospital level. Identification of demonstrably achievable obstetric intervention rates may help prioritise interventions to enhance maternity care.

Back to top

Validation and Impact of the Four Hour Rule/NEAT in the Emergency Department: A Large Data Linkage Study Dr Roberto Forero, Simpson Centre for Health Services Research, University of NSW

Access blockage and Emergency Department (ED) overcrowding are the most serious issues confronting EDs in the developed world, which compromise quality and timeliness of patient care. The National Emergency Access Target (NEAT) required that by 2015, 90% of patients must spend less than four hours in the ED from arrival to admission, transfer or discharge when is clinically appropriate to do so. The purpose of this project therefore was to assess the impact of the Four Hour NEAT policy in reducing access block and ED

overcrowding before and after its implementation, develop a long term partnership to reduce the harmful effects of access block and ED overcrowding on patients, and promote evidence based policy interventions for future research at the national and international level.

This project used data linkage to explore the incidence rates of ED presentations, demographic characteristics, procedures and other patterns of care of patients admitted through ED before, during and after the policy implementation of the Four Hour Rule/NEAT was used. A cohort of presenting patients in the NSW Emergency Department Data Collection between 2005 and 2013 at one of the six NSW hospitals (Westmead, John Hunter, Liverpool, Royal North Shore, Prince of Wales and Mount Druitt), and/or all presenting patients in the ACT Emergency Department Data Collection between 2005 and 2013 at Canberra Hospital or Calvary Hospital, was linked by the CHeReL to the NSW Admitted Patient Data Collection, NSW Registry of Births Deaths and Marriages death registrations, Cause of Death Unit Record File, ACT Admitted Patient Collection, and both NSW and ACT Ambulance datasets.

This research will provide evidence to generalise interventions across hospitals for addressing problems associated with deleterious delays in relation to hospital overcrowding. Through this study a framework for improving ED performance will be developed together with a long term strategy for maintaining and sustaining improvements in the system. The study will introduce complex system science methods that will guide the implementation of strategies for managing ongoing service improvement interventions at the clinical team, hospital, regional and national levels.

Back to top

Early childhood development and beyond Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

Children's early developmental outcomes are well-known to play a significant role in their long-term education achievements and occupation attainment. Socio-demographic characteristics such as a child's individual characteristics and their home experiences influence early developmental outcomes. Despite the growing body of evidence in this area, there are still substantial gaps in the knowledge base.

This study examines the role of individual, home and socio-demographic factors on child development outcomes, and their links with subsequent academic achievement. Two studies will be undertaken to investigate the association between individual, home and related characteristics and developmental outcomes; and the links between early childhood development and academic outcomes.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets linked by the CHeReL used in this study were the NSW

Perinatal Data Collection; the NSW Pharmaceutical drugs of addiction system; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Early childhood sets the foundation for social, physical, emotional, cognitive, and academic development. A healthy start to life ensures children have the foundation and basis for lifelong learning and educational achievement. This project will provide important information about early development among NSW children and will demonstrate links between developmental outcomes and later academic outcomes. Findings may contribute to understanding areas of early development that require greater societal and educational support.

Back to top

Understanding the impact of social, economic and environmental factors (SEEF) on the morbidity and mortality of Australians in mid-later life: what are the opportunities for prevention? Professor Adrian Bauman, Prevention Research Collaboration, University of Sydney

The SEEF Study is a sub-study of the 45 and Up Study exploring in detail the relationship between the economic, geographic, social and lifestyle factors such as mental health, smoking, physical activity and obesity on health service use, morbidity and mortality. The goal was to undertake integrated analyses of the impact of social, economic and environmental factors on the health of Australians in mid to later life in order to identify critical intervention points for preventing disease and ameliorating disadvantage, ill health and morbidity in older Australians.

The SEEF study added value to the existing 45 and Up cohort of 266,848 people by collecting additional self-reported information from a sub-sample of 60,404 adults to enable detailed investigation of social, economic and environmental factors. The CHeReL linked SEEF Study data and the baseline 45 and Up Study to the NSW Admitted Patients Data Collection, NSW Emergency Department Data Collection, NSW Central Cancer Registry, NSW Registry of Births Deaths and Marriages death registrations and Cause of Death Unit Record File. Medicare Benefits Scheme and Pharmaceutical Benefits Scheme data was linked through the 45 and Up Study by the Sax Institute.

SEEF subprojects together investigated air pollution, traffic exposures, social interaction, medication use, emergency department visits, hospitalisation and deaths, providing data on the effects of social, economic and environmental factors on health outcomes that are specific to the Australian context, adding to the knowledge base internationally. In addition, the SEEF Study aimed to build a simulation model that would allow the prediction, over the next 30 years, of the trajectory of the NSW population over age 45 in terms of health conditions,

health services use and health care expenditures. This model would then be used to study the impact of reducing socioeconomic and geographic inequalities and a variety of prevention strategies on the incidence and prevalence of chronic conditions (such as cardiovascular disease, diabetes and stroke), of their distribution and the associated health service use and expenditure.

Back to top

Emerging issues in obstetric care Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

Changing risk profiles of mothers (increasing age and chronic diseases) and their babies (increasing infant size, twins, preterm infants), differences in access, obstetric practices and the availability of maternity care may have significant impact on maternal and infant health outcomes. Current and emerging issues that require investigation include rising trends in elective deliveries (planned pre-labour caesarean section or induction of labour), increasing trend in births before the due date, outcomes of variation in maternity practice, recurrence and impact of obstetric interventions on current and future pregnancy outcomes, and the risk of recurrence of adverse pregnancy outcomes. There is also limited information on the implications of these interventions on long-term child health and development and future pregnancies.

The seven studies proposed within this project will investigate maternal and child outcomes associated with hypertensive disorders of pregnancy; changing patterns of gestational age distribution; maternal outcomes for pregnancies of 20-24 weeks duration; maternal and neonatal outcomes for women with previous pregnancy complications or of advanced maternal age; the impact of inter-pregnancy interval on subsequent pregnancy outcomes following a 2nd trimester loss; and outcomes of abdominal surgery during pregnancy. The burden of disease, trends and predictors, and risk of adverse pregnancy outcomes, subsequent maternal health and infant and child outcomes will be assessed for each project.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets used in this study were the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Findings from the studies will provide information to inform clinical decision making, improving the quality and safety of maternity services and informing maternity care policy and practice.

2014

Back to top

Prenatal origins and health outcomes. Dr Natasha Nassar, The Kolling Institute, University of Sydney

Rates of male reproductive congenital anomalies and testicular cancer are rising. There is evidence that these conditions share a common origin in foetal life through impaired production or disrupted release of androgens. Maternal, prenatal or familial factors or their combined effects may influence androgen levels/actions during foetal sex development resulting in male reproductive congenital anomalies; while surgical repair and correction of these anomalies may lead to increased risk of hospitalisations and poor child health, and potentially poor male reproductive health in child and adulthood.

The aim of this study is to investigate the role of maternal, prenatal and familial factors associated with hypospadias and cryptorchidism; and investigate the health outcomes for infants diagnosed with these conditions including outcomes of surgical repair, patterns, trends and determinants of subsequent hospitalisations, and health later in childhood.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data linkage helps to overcome many limitations of previous studies of these conditions as it facilitates the assessment of pregnancy factors and subsequent childhood health outcomes, not possible with most standalone data collections. Data sets used in this study were the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Findings from the study will provide valuable information about male reproductive disorders, identify maternal and perinatal risk factors, and determine long term fertility outcomes of affected males. This will aid clinical counselling for risk reduction during pregnancy and will inform prevention initiatives prior to pregnancy.

Back to top

Social interaction, psychosocial and life distress, cardiovascular, and morbidity and all-cause mortality Associate Professor Philayrath Phongsavan, Sydney School of Public Health and Charles Perkins Centre, University of Sydney

Social relationships are critical for maintaining health and well-being. Individuals with stronger social relationships have an increased likelihood of survival compared to those with weaker relationships; conversely social isolation is associated with increased all-cause mortality, cardiovascular disease and psychological distress. However, what is not clear is whether social isolation and psychological distress independently contribute to mortality, or if psychological distress amplifies the effect of social isolation on mortality. Furthermore stressful life events can act as a trigger for a cardiovascular event and a risk factor for mortality; but it is not clear whether people who experience stressful life events but are more socially connected have a lower risk of morbidity and mortality.

This project aims to examine the role of social interaction or isolation and psychological and life event distress in predicting cardiovascular and stroke morbidity and all-cause mortality, and the interaction between these factors. It will also examine if social interaction moderates the effects of psychosocial and life event distress on mortality and morbidity, or confers any positive effects on health regardless of psychosocial and life event distress. The Socioeconomic and Environmental Factors Study (SEEF) was undertaken as a sub study of the 45 and Up Study. For this project the CHeReL linked records from the SEEF study and the 45 and Up Study baseline questionnaire data, to the NSW Admitted Patient Data Collection and the Register of Births Deaths and Marriages death registrations.

Findings from the study will have important policy implications for informing public efforts to reduce social isolation in order to minimise the risk of premature morbidity and mortality.

Back to top

Analysis of the reproductive outcomes of women with attention deficit hyperactivity disorder Dr Alison Poulton, University of Sydney

Although it is more frequently diagnosed in children, attention deficit hyperactivity disorder (ADHD) is becoming increasingly recognised as a problem associated with impairment in functioning in adults. As women enter their reproductive years, concerns arise about the impact of these medications on foetal growth. There are very little data on the reproductive outcomes of women with ADHD and more information is needed in order to understand the short and long term risks.

This study aims to compare the reproductive outcomes of women with ADHD, based on their history of treatment with stimulant medication, with all women giving birth in NSW during the period 1994-2010 and with matched controls. Cases were women of childbearing age (from early teens to women in their forties) during the study period, who had a diagnosis of ADHD based on prescription of stimulant medication in the Pharmaceutical Drugs of Addiction System (PHDAS). The CHeReL linked these records to the NSW Perinatal Data

Collection and the NSW Registry of Births Deaths and Marriages birth registrations. The CHeReL also selected 5 controls for each case from the PDC data but who did not occur on the PHDAS, to compare perinatal data of women not diagnosed and treated for ADHD.

Findings from the study will provide clinicians with information to guide clinical decision making, enabling them to assess the benefits of continuing medication versus discontinuing during pregnancy.

Back to top

Single Practice, Multiple Hospital Review of Treated Aortic Aneurysms from 1987-2014 Dr Raymond Englund, R and R Englund Pty Ltd.

This retrospective practice audit uses linked data to ascertain short and long term outcomes following surgery for Abdominal Aortic Aneurysm repair. The audit spans almost 30 years, during which time the management of abdominal aortic aneurysm disease has changed significantly from open surgery to endovascular aortic aneurysm repairs.

Essentially the key outcome from aortic aneurysm surgery is duration of survival. The CHeReL linked a clinical practice registry to the ABS Mortality Data and NSW Registry of Births Deaths and Marriages death data. This linkage will enable complete follow up of all patients treated during the time period for accurate survival calculations and also facilitate individual quality control for the surgical practice of interest.

Back to top

Management and outcomes of multi-fetal pregnancies. Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

Multi-fetal pregnancies have higher rates of infant morbidity and mortality and maternal morbidity. Infants are more likely to be born prematurely and suffer intra-uterine growth restriction, and they use a disproportionate amount of maternity and neonatal services. Optimising decision-making for

Multi-birth pregnancies has the potential to reduce morbidity for infants and mothers and to reduce the burden on health services. However there is limited evidence of sufficient robustness to guide decisions about delivery at or near term.

The aim of this study is to examined the distribution, trends and effects of timing and mode of delivery of multi-fetal pregnancies on birth outcomes, childhood outcomes, antepartum, intrapartum and postpartum maternal morbidity, and longer term maternal morbidity. Outcomes will be compared to single birth pregnancies.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets used in this study were the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Data linkage provides the opportunity to examine even rare outcomes such as perinatal death in this population. Findings from the studies will provide information to inform clinical decision making, improve the quality and safety of maternity services and inform maternity care policy and practice.

Back to top

Cervical cerclage in NSW: trends, risk factors and outcomes. Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

Preterm birth prior to 37 weeks gestation complicates approximately 8% of pregnancies in NSW and is a major cause of perinatal mortality and morbidity. Cervical cerclage is a surgical procedure where a suture is placed around or above the cervix in an attempt to prevent cervical dilation or shortening, used to prevent preterm birth. The timing of insertion is unknown in Australian maternity populations; as is the proportion of women who have a second trimester loss or go on to have a birth ≥20 weeks gestation. Although cervical cerclage reduces the incidence of recurrent pre-term birth in women at risk, uncertainty exists about who is at high risk, how to treat them, and the long term impact of cerclage on the baby. In addition cervical cerclage carries a number of risks for the woman and baby.

This project aims to describe the patterns of use of cervical cerclage and the maternal health, reproductive history and pregnancy characteristics of women undergoing it; describe the range of services where cerclage procedures are performed; assess trends over time in first time use of cerclage; and describe pregnancy outcomes by gestational age at insertion. A control group of women at high risk of miscarriage or preterm birth who did not have cerclage will provide a comparison group. The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets linked by the CHeReL used in this study were the NSW Admitted Patient Data Collection; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; and the NSW Perinatal Death Reviews.

This study will provide information on the use and outcomes of this procedure, in particular the probability of the fetus reaching a viable gestation age. If there is evidence of overall benefits from cerclage, it may be possible to identify pregnancy subgroups where the benefits are more likely. This will improve the

quality of information available to couples and their health care providers and potentially reduce the number of very preterm infants

Back to top

Costs and benefits of prevention: Implications on the distribution of health. Associate Professor Federico Girosi, University of Western Sydney

Over the next 30 years chronic conditions will impose an increasing burden on the population in terms of health and disability status, and use of and cost to health services. Prevention has the potential to make a significant contribution to improving health outcomes and health related quality of life, reducing health inequalities and minimising unnecessary demand for health care services. However the issue of how much preventive intervention can improve the distribution of health has not been studied quantitatively. Therefore the aim of this study is to develop a predictive model of the long term trajectory of the population in terms of health conditions, health service use and expenditure. Using scenario modelling, the effects of preventive policies will be explored by creating appropriate counterfactual scenarios for various chronic health conditions, risk factors and socioeconomic and geographic inequalities to model the changes under each set of conditions.

The Costs and Benefits of Prevention (CBOP) study is a sub study of the 45 and Up Study under the Socioeconomic and Environmental Factors study (SEEF) program of work. For this project the CHeReL linked records from the SEEF study and the 45 and Up Study baseline questionnaire data, to the NSW Admitted Patient Data Collection, the NSW Central Cancer Registry and the Register of Births Deaths and Marriages death registrations and ABS Mortality Data. This project will provide a visualisation of the future trajectory of the population and will identify factors to take into account when designing prevention programs. It will also help clarify the role that prevention can play in reducing health inequalities.

Back to top

Tobacco policy reform and population-wide smoking cessation programs in NSW: The impact on smoking during pregnancy Dr Alys Havard, Centre for Big Data Research in Health, UNSW Sydney

Smoking rates in pregnancy have declined over the last decade, but the reasons for the decline have not been determined. Changes in antenatal care and clinical guidelines recommending women are offered smoking cessation interventions as part of antenatal care may be partially responsible; however as women who smoke early in pregnancy and subsequently quit are recorded on administrative perinatal data as ‘smoking’ during pregnancy, activities that encourage quitting after conception cannot account for the reduction in smoking during pregnancy.

Population wide antismoking efforts such as graphic health warnings, taxation and bans on smoking in enclosed spaces may be responsible for an increased awareness of the harms of smoking during pregnancy but this remains untested.

Therefore this study aims to assess the effect of tobacco policy reforms and other population wide anti-smoking measures on the prevalence of smoking at time of conception, and the proportion of obstetric complications attributable to maternal smoking. To facilitate this study the CHeReL linked records from the NSW Perinatal Data Collection, the NSW Admitted Patient Data Collection, and the NSW RBDM death registrations.

The findings from this study will provide important information for guiding decisions about future population-wide smoking cessation activities that are capable of reaching women who will go on to bear children.

Back to top

Is an impact of the Stepping On program on falls evident in routinely-collected data? Dr Serene Paul, The George Institute for Global Health and The University of Sydney

Currently, fall-related injuries in older people are a significant source of morbidity and health expenditure. The Stepping On program has demonstrated effectiveness in reducing falls in community-dwelling older people.
The NSW Ministry of Health has committed significant resources to implementing this fall prevention program across the state. Routinely collected data may be able to detect an effect of the Stepping On program rollout on fall-related hospitalisations, including injuries. This study will explore the impact of the Stepping On program on fall rates in NSW using routinely collected data.

This study utilises a stepped wedge study design involving assessment of fall-related hospitalisations (including injuries) at multiple time points to compare fall rates in NSW prior to the introduction of the Stepping On program and following its implementation in each Local Health District. Routinely collected data from the NSW Admitted Patient Data Collection (APDC) from 1 July 2005 to 31 December 2013 has been utilised, with data for 1 January 2014 to 30 June 2015 (to be updated in 2016) allowing comparison for a minimum of three years prior to and following the introduction of the Stepping On program in each Local Health District.

Back to top

Hip arthroscopic surgery rates in New South Wales Dr Francis Connon, NSW Health

The precise indications for hip arthroscopic surgery are not yet clear. The surgery is commonly used for conditions such as femoro-acetabular impingement and labral tears, but the exact role is still not completely

established. This project seeks to determine practice variation with regards to arthroscopic hip surgery and the number of arthroscopies performed in each financial year over the study period. Data will be analysed with regards to: 1) comparison with growth in the state population in that period; 2) comparison between arthroscopy rates in public and private settings; 3) complication rates based on in-hospital complications recorded and readmissions data; and 4) comparison between arthroscopy numbers performed in NSW and those performed in Victoria (using data already obtained by a separate group of investigators).

The project is a retrospective observational cohort study reviewing the number of operations performed and comparing: year by year change, variation by postcode, variation according to public vs. private hospitalisation. The study will also review the associated complication rates for inpatients, those requiring increased length of stay, and those requiring readmission within 90 days. A cohort of patients aged over 18 years old at admission who were discharged following hip arthroscopic surgery in NSW from July 2000 to June 2014 were linked to the NSW Admitted Patient Data Collection, NSW Registry of Births Deaths and Marriages death registrations, ABS Mortality data collection.

Back to top

Prenatal origins and health outcomes. Dr Natasha Nassar, The Kolling Institute, University of Sydney

Rates of male reproductive congenital anomalies and testicular cancer are rising. There is evidence that these conditions share a common origin in foetal life through impaired production or disrupted release of androgens. Maternal, prenatal or familial factors or their combined effects may influence androgen levels/actions during foetal sex development resulting in male reproductive congenital anomalies; while surgical repair and correction of these anomalies may lead to increased risk of hospitalisations and poor child health, and potentially poor male reproductive health in child and adulthood.

The aim of this study is to investigate the role of maternal, prenatal and familial factors associated with hypospadias and cryptorchidism; and investigate the health outcomes for infants diagnosed with these conditions including outcomes of surgical repair, patterns, trends and determinants of subsequent hospitalisations, and health later in childhood.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data linkage helps to overcome many limitations of previous studies of these conditions as it facilitates the assessment of pregnancy factors and subsequent childhood health outcomes, not possible with most standalone data collections. Data sets used in this study were the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; the NSW Perinatal

Death Reviews; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Findings from the study will provide valuable information about male reproductive disorders, identify maternal and perinatal risk factors, and determine long term fertility outcomes of affected males. This will aid clinical counselling for risk reduction during pregnancy and will inform prevention initiatives prior to pregnancy.

Back to top

Developing indicators of cancer progression and recurrence in NSW using NSW Cancer Registry data, Admitted Patients Collection data, Emergency Department data, and MBS and PBS Health Insurance data Professor David Currow, Cancer Institute NSW

There is strong demand for population-based monitoring data on cancer progression/recurrence to gain early markers of treatment outcomes, but few examples of these data exist world-wide. Because collecting these data from clinical centres is difficult to sustain, data linkage of administrative datasets has been proposed as an alternative strategy for data collection, including linking data from cancer notifications, pathology reports, hospital and radiotherapy records, and health insurance records.

The aims of this study are: 1) To use linked administrative data to develop indicators of the fact and timing of cancer progression/recurrence; 2) To compare the accuracy of these indicators with reported data from a subsample of patients and clinicians; and 3) To investigate how linked data from different sources should be weighted by data source to maximize predictive accuracy.

This study linked a cohort of 45 and Up Study participants who had ever had a diagnosis of cancer (determined via data linkage to the NSW Central Cancer Registry), to other records from the NSW Cancer Registry, NSW Clinical Cancer Registries, NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, Registrar of Birth Deaths and Marriages death registrations, ABS Mortality data collection. Medicare Benefits Schedule (MBS) treatment and Pharmaceutical Benefits Schedule (PBS) cancer-related systemic therapy data were provided via the 45 and Up Study.

Back to top

NSW Child Development Study: Record Linkage 2 – Feasibility Study Prof Vaughan Carr

The New South Wales Child Development Study (NSW-CDS) is a longitudinal investigation of a population cohort of ~94,000 children that aims to identify childhood vulnerability and protective factors which predict a variety of later

health and social outcomes in adolescence and young adulthood. This feasibility study tested the record linkage capacity of the Middle Childhood Survey, a self-report questionnaire measure of children's mental health and well-being completed by 645 ~11-year-old children in 11 NSW primary schools during 2014. The Middle Childhood Survey was linked to perinatal records and birth registration records held in the Master Linkage Key, and an external data collection of education data, with mothers and fathers of the children identified for linkage via the birth registrations.

This feasibility study was critical to the success of the population linkage study conducted in 2016, in which the records obtained in the population administration of the Middle Childhood Survey will be linked as part of the NSW Child Development Study cohort (~N=87,000).

Back to top

Opioid Dependence: Candidate Genes and G x E Effects (Comorbidity and Trauma Study – CATS) Prof Louisa Degenhardt, NHMRC Principal Research Fellow, National Drug and Alcohol Research Centre, University of New South Wales

The Comorbidity and Trauma Study (CATS) interviewed 1487 opioid-dependent individuals on opioid substitution therapy (OST) and 515 control subjects between 2004 and 2008. Participants completed face-to-face, structured psychiatric interviews that included assessments of drug dependence and childhood trauma, as well as other psychiatric disorders. The aim of this study is to examine causes and predictors of mortality, and patterns of engagement with OST among the CATS cohort. For this study the CHeReL linked the CATS cohort with the National Death Index, the Pharmaceutical Drugs of Addiction System, the NSW Admitted Patient Data Collection and the NSW Emergency Department Data Collection. The linkage rates were an important part of this study as the CATS data set contained many incomplete identifiers.

Back to top

Essential clinical annotation for NSW Biobanks through data integration with clinical and administrative datasets Professor Anna DeFazio and Professor Christine Clarke, University of Sydney, Westmead Millennium Institute and Department of Gynaecological Oncology, Westmead Hospital

Realising better health outcomes and economic gains, through closer alignment of medical research and health care delivery, depends in part on a sustainable and efficient biobanking system within NSW. Longitudinal data linked to

biospecimens are invaluable components of such a system, yet currently the processes for collection and retention of longitudinal data are laborious, time-intensive and costly. Moreover, the data held by biobanks can be incomplete and/or inaccurate. The purpose of biobanks is to have a 'research ready' collection of material and data, processed and stored under criteria that optimise the potential for sample use, protect donor privacy, and provide an accurate data set relating to the samples, in order to expedite research programs. Accordingly, this study aimed to test and document the feasibility and validity of augmenting the current methods of data collection for biobanks and investigated the most effective way to streamline and improve the process of collection. The ultimate goal being improved quality of translational research that can be conducted using biobanks samples.

Using cohorts of consenting patients from the Westmead Gynaecological Tissue Bank (GynBiobank) and the Australian Breast Cancer Tissue Bank (ABCTB), this pilot study investigated the feasibility of linking cancer biobanks databases with clinical data routinely collected in NSW Administrative Datasets by analysing and comparing how these data items are collected, and testing the feasibility of accessing and updating data relevant to biobanks through linkage with NSW databases via the CHeReL. Biobank data was linked to the NSW Central Cancer Registry, NSW Admitted Patient Data Collection, and NSW Registry of Births, Deaths and Marriages death registrations.

Linking NSW health data to the biobank data may enable clinical parameters and patient follow-up to be conducted in a cost-effective, efficient manner in the future. It may also enable standardisation of the clinical data collected for each biobank. This will facilitate accurate, consistent data to be provided on specimens with the aim of expediting translational research. The findings from this study are intended to provide the potential evidence for supporting the adoption of routine longitudinal linkage into biobank practices, and the development and implementation of state legislation to support this process.

Back to top

Establishing integrated data for stroke to enable comprehensive monitoring of care and patient outcomes to provide evidence for clinical practice improvement Associate Professor Dominique Cadilhac, School of Clinical Sciences, Monash University

In Australia about 50,000 people suffer a stroke each year. Research has been used to show that adherence to evidence based clinical guidelines, such as admission to a stroke unit, can reduce in-hospital mortality and improve outcomes. However, evidence based care is not always provided in clinical practice. Such discrepancies in care quality are concerning given that variation in patient management has been shown to adversely affect health outcomes and

lead to ineffective use of health care resources, including increases in hospital readmissions and Emergency Department presentations.

The Australian Stroke Clinical Registry (AuSCR) is a national clinical quality registry of patients with acute stroke and is a collaborative national effort to monitor, promote and improve the quality of acute stroke care. As part of an NHMRC partnership project with the Florey Institute of Neuroscience and Mental Health (AuSCR Data Custodian), the National Stroke Foundation and Queensland Health called Stroke 123 (GNT1034415), investigators of this study aimed to determine the value of linked data in describing variations in the quality of acute stroke care, and describe any variations in costs which may be related to the quality of care. In order to assess the quality of stroke information by comparing AuSCR data with hospital and emergency admission data, the CHeReL linked the AuSCR data collection with the NSW Admitted Patient Data Collection and NSW Emergency Department Data Collection. The respective data linkage agencies of Queensland, Western Australia and Victoria have also linked AuSCR data to hospital and emergency data collections and a project specific unique national linkage key will be used to merge these datasets. This study will be the first to achieve national cross-jurisdictional data linkage between a clinical quality registry that is not managed by government and hospital health information data in Australia.

Data linkage value adds to AuSCR because it is a minimum dataset of national indicators prioritised for stroke and when the datasets are merged can provide more comprehensive data for routinely monitoring acute stroke care in hospitals whereby the continuum of stroke care across multiple sectors can be tracked. This is particularly important for patients with stroke since multiple interactions across a range of healthcare facilities and jurisdictions are common.

This study also provides the evidence for the feasibility of capturing and using a range of data for other chronic complex conditions where multiple interactions with the health system, between and within different jurisdictions, are typical for each patient. The data linkage and quality improvement frameworks developed as a consequence of this work have the potential to improve the quality of care and outcomes for a range of chronic diseases, not just stroke.

Back to top

Air pollution, traffic exposures and mortality and morbidity in older Australians (APTEMA) study Professor Bin Jalaludin, Centre for Research, Evidence Management and Surveillance, Liverpool Hospital

There is increasing recognition that exposure to high levels of air pollution causes serious adverse health effects and is an important risk factor for cardiovascular disease (CVD), pneumonia, chronic respiratory disease and cancer. There are also increased risks of all cause, cardiovascular, stroke,

respiratory and lung cancer mortality. The costs of this burden are substantial and in Australia the health costs associated with motor vehicle related air pollution are estimated to be $1.5 to $3.8 billion. Nevertheless despite the growing body of evidence, the health effects attributable to long term exposure to traffic related air pollution are still classified as 'suggestive' rather than causal, leaving gaps in the evidence to be investigated.

Therefore, the overarching aim of the Air Pollution, Traffic Exposures and Mortality and Morbidity in Older Australians (APTEMA) Study is to investigate the association between long term exposure to air pollution and adverse health outcomes in older Australians. Specifically the study will quantify the association between long term exposure to air pollution and prevalence, incidence of self-reported chronic disease, and medications prescribed for respiratory and cardiovascular diseases; hospitalisation and emergency department attendance attributed to respiratory disease, stroke and CVD; and mortality due to all causes, respiratory, cardiovascular diseases, stroke, all cancers and lung cancer. The specific pollutants or sources of air pollution most strongly contributing to health outcomes will also be investigated, along with the specific attributes and co-morbid conditions that confer greater susceptibility to long term adverse health effects.

The Socioeconomic and Environmental Factors Study (SEEF) is a sub study of the 45 and Up Study. For this project the CHeReL linked records from the SEEF study and the 45 and Up Study baseline questionnaire data, to the NSW Admitted Patient Data Collection, the NSW Central Cancer Registry and the Register of Births Deaths and Marriages death registrations.

This project has considerable potential to influence health and environmental policy. It will provide valuable information on the long term effects of exposure to health pollution and in particular will be able to examine associations at the lower end of the exposure-response relationship; which is particularly relevant for standard setting.

Back to top

The impact of dementia on access to and outcomes from rehabilitation following lower limb fracture-related hospitalisations: Study 1 Associate Professor Rebecca Mitchell, Australian Institute of Health Innovation, Macquarie University

Falls and fall-related injury in older people continue to challenge health and social care systems on a worldwide basis. Dementia has been consistently shown to increase risk of falls, with rates that are double that of cognitively intact older people. Older people with dementia have a four-fold increased risk of hip fracture and a three-fold increased risk of 6-month mortality following a fracture when compared to older people without this condition. Relatively little is known about the care provided for patients with dementia who are admitted to

hospital following a fracture but there is a perception that access to rehabilitation is often restricted due to a belief that the presence of dementia has a direct impact on their ability to engage and benefit from a structured approach to rehabilitation. Functional recovery of demented patients with hip fractures can be as good as those without dementia and discharging patients to rehabilitation facilities results in better functional outcomes compared to those discharged to long-term residential facilities. Whilst true that dementia will potentially have an impact on rehabilitation goals, there is evidence that a dementia specific approach to care can be effective in improving daily function for the person with dementia and a sense of competence for the carer.

Access to, and outcomes from, rehabilitation for lower limb injuries in older people with and without dementia in NSW are not clear. An accurate snapshot of the incidence and characteristics of rehabilitation and related follow-up care in NSW is needed for individuals sustaining lower limb injuries, particularly severe injuries such as fractures, and the determination of whether use of rehabilitation differs for those individuals with and without dementia needs to be explored.

This retrospective study examined access to and outcomes from rehabilitation following a fracture in older people with dementia. The cohort was taken from the NSW Sub-acute Non-acute Patient (SNAP) data collection for individuals (aged 50 years and older) with lower limb injuries who were hospitalised between 2003 and 2013. The CHeReL linked these data with the NSW Admitted Patient Data Collection and NSW Registry of Births, Deaths and Marriages death registrations. Overall, this research will better inform treatment practices, health system planning and resource needs and future research priorities.

Back to top

Socioeconomic status, depression and risk of stroke: analysis of 750,000 participants from two prospective cohort studies Dr Caroline A Jackson, School of Population Health, University of Queensland and Usher Institute for Population Health Sciences and Informatics, University of Edinburgh

By 2020, cardiovascular disease and major depressive disorders are projected to be the two leading causes of morbidity worldwide. Stroke is the third leading cause of morbidity and mortality worldwide. Incidence of both stroke and depression have been found to be higher among lower socioeconomic groups in Australia and elsewhere, highlighting the excess burden of disability within these less advantaged and more vulnerable groups. Conventional vascular risk factors, such as hypertension and smoking are estimated to account for 60-80% of ischaemic stroke cases. The role of other potential risk factors in explaining the remaining 20-40% of stroke cases remains unclear. Two such factors, depression and socioeconomic status (SES), are known to increase

stroke risk, but it is unclear whether they are independently associated with stroke risk. Also, it is unclear whether there are age and gender differences in the association between depression and stroke. Furthermore, the mechanisms underlying the association between SES and stroke, and the extent to which depression contributes to the causal pathway, remain poorly understood.

This study obtained data from two contemporaneous population-based cohort studies that were set up to investigate the causes and consequences of disease (UK Biobank and NSW 45 and Up Study). Both cohorts follow participants for major health outcomes via data linkage to hospital admission records and death records. The CHeReL linked the 45 and Up Study to the NSW Admitted Patient Data Collection, ACT Admitted Patient Collection, NSW Registry of Births Deaths and Marriages death registrations and Cause of Death Unit Record File. These data were then used to explore age and gender differences in the associations between each of SES and depression, and stroke, and to investigate hypothetical pathways through which SES may operate to increase stroke risk, with examination of the potential contributory role of depression.

Back to top

Seeding success: identifying factors that contribute to positive early childhood health and development in Aboriginal children Professor Louisa Jorm, University of New South Wales, and Dr Kathleen Falster, Australian National University

Australian Aboriginal children are more likely than non-Aboriginal children to have markers of developmental vulnerability at school entry, tracking through to poor school outcomes and disadvantage in later life. The Seeding Success study aims to identify key drivers of positive early childhood development in Aboriginal children, and supportive features of local communities and early childhood service provision. The study includes an almost complete population cohort of children (N=154,936) who started school in New South Wales (NSW) in 2009 or 2012, and were born in NSW, identified by linking Australian Early Development Census data to perinatal and birth registration datasets. Early childhood health and development trajectories are being constructed via linkage to administrative datasets relating to birth outcomes, congenital conditions, hospital admissions, emergency department presentations, use of mental health services, school enrolments and contact with child protection and out-of-home care services. Analyses now in progress, applying multilevel modelling techniques, are investigating the following in relation to early childhood development outcomes in Aboriginal compared with non-Aboriginal children: maternal and perinatal factors; preschool attendance; and age at school entry. In partnership with policy agencies, we will use the linked data to assess the impact of two current NSW government programs that aim to address early childhood disadvantage (NSW Aboriginal Maternal and Infant Health Service and the Brighter Futures program). These analyses will use propensity matching methods and interrupted time series analysis to identify comparison areas and

groups and to compare outcomes between areas and groups. The findings will be relevant to those working in the health, early childhood, community services and education sectors.

Back to top

Observing Recurrent Incidence of Adverse Outcomes following Hospitalisations (ORION) Dr Isuru Ranasinghe, The University of Adelaide

As a leading cause of death, disability, and health care expenditure, hospital-based cardiovascular care has a significant impact on the Australian health care system. However, hospital cardiac care varies considerably and important well accepted measures of care quality such as death or unplanned return to hospital are rarely assessed. ORION study seeks to developed robust methods to evaluate these outcomes along with hospital level variation and temporal changes in these measures.

Selecting records for patients with common cardiovascular conditions and procedures, the CHeReL linked data from the NSW Admitted Patient Data Collection and the ACT Admitted Patient Collection, the NSW Emergency Department Data Collection and the ACT Emergency Department Information System, the NSW Registry of Births Deaths and Marriages death registrations and ACTRegistry of Deaths. Results from this study helped to inform the extent of variation across Australian hospitals and the impact of this on patients. This offers opportunities to identify targets for quality improvement efforts, improve patient care and reduce health care costs.

Back to top

The safety of pharmacotherapies for smoking cessation Dr Alys Havard, Centre for Big Data Research in Health, UNSW

Smoking is the leading preventable cause of morbidity and premature mortality in the developed world, and a major risk factor for cardiovascular disease in particular. First line pharmacological smoking cessation aids are among the most cost effective preventive healthcare measures available, in terms of cost per life saved. Although varenicline, bupropion and nicotine replacement therapy (NRT) are available to Australians at a subsidised price, through the Pharmaceutical Benefits Scheme (PBS), highly publicised concerns about the safety of these medications are likely to be limiting their use. Robust evidence from large samples of real-world pharmacotherapy users is needed to establish whether these safety concerns are justified.

This study aimed to investigate the safety of smoking cessation medications by examining whether varenicline or NRT are associated with increased risk of cardiovascular events relative to bupropion; varenicline or bupropion are associated with increased risk of adverse psychiatric outcomes relative to NRT;

and bupropion is associated with increased risk of seizures relative to varenicline and NRT.

The CHeReL linked the 45 and Up Study to the NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, NSW Registry of Births Deaths and Marriages death registrations, Cause of Death Unit Record File and NSW Mental Health Ambulatory Data Collection.

This study will provide information on whether more widespread use of any of these products is appropriate, and clinically relevant information about whether smokers should receive more encouragement to use smoking cessation pharmacotherapies. The findings will inform clinical guideline development, thereby allowing smokers and their physicians to make informed decisions. The findings will also be relevant to pharmaceutical policy and other policy decisions regarding the management of smoking in Australia.

Back to top

Population level relevance of risk factors for cancer in Australia Dr Maarit Laaksonen, Centre for Big Data Research in Health and University of NSW

This project sought to describe the proportion incident cancers that were attributable to lifestyle exposures such as smoking, alcohol consumption, poor diet, overweight, physical inactivity, and reproductive and hormonal factors.

Cancer prevention is most effective when strategies target modifiable risk factors responsible for the greatest number of cancer cases in the population of interest. Although several studies estimating the relative risks associated with modifiable risk factors for different cancers have been published, both in Australia and internationally, their relative importance at the population level has not been sufficiently examined.

The Population Attributable Fraction (PAF) is a statistical measure which integrates the strength of association (relative risk) between exposure and the cancer of interest, and the prevalence of exposure in the population. Using a flexible method developed by the authors for the estimation of PAF and its confidence interval from cohort studies, PAF was used to evaluate and compare the cancer burden attributable to different risk factors at the population level.

Participants pooled from seven established Australian cohorts (the 45 and Up Study, the Melbourne Collaborative Cohort Study, the Australian Longitudinal Study on Women's Health, the Australian Diabetes, Obesity and Lifestyle Study, the North West Adelaide Health Study, the Blue Mountains Eye Study, and the Concord Health and Ageing in Men Project) were linked to the Australian Cancer Database (ACD) and the National Death Index (NDI). The CHeReL linked records from the 45 and Up Study and the NSW Admitted Patient Data Collection, and provided these to the Australian Institute of Health and Welfare for linkage to the ACD and the NDI.

Use of this method provides more accurate estimates of the avoidable cancer burden, essential in prioritising interventions and policies aimed at preventing cancer in Australia.

Back to top

Cognitive decline in the elderly and health service utilisation Professor Henry Brodaty, University of NSW

People with dementia are major users of medical and hospital services; experiencing three times higher hospitalisation rates, and lengths of stay almost twice as long as cognitively intact people of similar age. However, in the early stages of dementia there can be a mix of increased and reduced use of medical services that may vary with the circumstances of the individual. Furthermore, variation in usage of services may in turn be associated with progression of mild cognitive impairment (MCI) and dementia.

Using an established cohort of older people enrolled in the Sydney Memory and Aging Study (MAS), this program of research, consisting of three studies, aimed to examine the health service utilisation, costs and health outcomes of people with and without MCI and dementia. Study 1 aimed to investigate the impact of acute hospitalisation events on cognitive and functional trajectory plus ascertain the extent to which factors associated with hospitalisation, illness, or patient co-morbidities influence cognitive decline following hospitalisation; Study 2 aimed to determine the impact of MCI on health care utilisation and costs over time; and Study 3 aimed to determine injury related health care usage and outcomes for people with and without MCI and dementia.

For this program of work, the CHeReL linked records from the MAS to the NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, and the NSW RBDM death data and ABS Mortality data.

The results of this project will provide information which could contribute to the development of clinical policy and health service planning to better support older adults with mild cognitive impairment.

Back to top

The relationship between psychosis and offending in New South Wales - A data-linkage study: implications for mental health policy development Dr Stephen Allnutt, Justice Health and Forensic Mental Health Network, NSWMinistry of Health and University of NSW

This project will provide insights into the relationship between psychosis and contact with the criminal justice system in NSW. Whilst the association between psychosis and violence is well documented, there had been no examination of the relationship between psychoses and offending in NSW. There are considerable costs involved in hospitalisation for psychosis, and in running the criminal justice system. Therefore, any new knowledge informing the pathways into the criminal justice system and the role of mental illness in this trajectory is of interest to health and criminal justice policy makers, and offers personal benefits to those in contact with the justice system and also the broader community.

The project will utilise NSW health service data, data from the NSW Bureau of Crime Statistics and Research (BOCSAR), and Corrective Services NSW data. CHeReL has linked the following data sources for this study: the NSW Bureau of Crime Statistics Reoffending Database (ROD), NSW Offender Integrated Management System (OIMS), the Mental Health Outcomes and Assessment Tool Collection (MH-OAT), and the Pharmaceutical Drugs of Addiction System: methadone subsystem (PHDAS), to the NSW Admitted Patient Collection (APDC), NSW Emergency Department Data Collection (EDCC), NSW Mental Health Ambulatory Data Collection (MH-AMB), and NSW Registry of Births Deaths and Marriages death registrations (RBDM). This linkage facilitated investigation into psychosis and subsequent offending behaviour uses a case-control design. Cases diagnosed with psychosis during a hospital admission or attendance at an ED will be followed up for possible subsequent offending behaviour and compared with controls with no psychosis from the NSW Electoral roll. Measurement of the proportion of prisoners with psychosis who had had contact with a community mental health service prior to incarceration, plus the post release rate and causes of mortality will also be examined.

The potentially modifiable nature of risk factors mediating the association between psychosis and offending behaviour has attracted a significant scientific and public interest. It is envisaged that findings from this and future research into the relationship between psychosis and offending will inform better policy development with the aim of reducing offending behaviours by

Back to top

The ‘Candida in Pregnancy Study (CiPS)’ – a randomised trial with pregnancy outcomes from routinely collected data Professor Jonathan Morris, The Kolling Institute

Prevention of preterm birth remains one of the most important challenges in modern maternity care. The ‘Candida in Pregnancy’ (CiPS) study is a cohort study of pregnant women with a positive screen for candidiasis that includes a nested randomised controlled trial (RCT). The cohort determines candida carriage rates in early pregnancy and factors associated with asymptomatic candidiasis, and

the RCT evaluates whether treatment of women with asymptomatic candidiasis reduces the preterm birth rate.

In order to obtain baseline and outcome data for women enrolled in CiPS, plus comparative data with women who do not have candidiasis, the cohort was linked to routinely collected data by the CHeReL, namely data from the NSW Admitted Patient Data Collection, the NSW Perinatal Data Collection, the NSW Registry of Births Deaths and Marriages death registrations, and the ABS Mortality data. In addition a mother-baby linkage was undertaken to all these data sets plus the NSW Registry of Births, Deaths and Marriages birth registrations and the NSW Perinatal Death Review. This linkage enabled a comparison of maternal and pregnancy characteristics, and outcomes among woman with asymptomatic candidiasis and those without candidiasis; plus an evaluation of the impact of treatment for candidiasis on preterm birth, other adverse pregnancy outcomes, and maternal health. A linkage to education data in the future will enable the assessment of child health and educational outcomes.

If the findings from this project demonstrate that treatment of asymptomatic candidiasis reduces preterm births this will change current practice internationally and will directly impact the management of every pregnant woman.

Back to top

Fall-related and other health service use in Stepping On participants and other older adults Professor Cathie Sherrington, The George Institute for Global Health and the University of Sydney

Thirty per cent of people aged 65 years and over fall annually, and these falls and fractures have a major impact on older people, their carers, health services and the community. With the ageing population the personal impact and health care burden associated with falls is predicted to increase. Currently, little is known about long term health service use in older fallers and such information has the potential to contribute to health service planning.

The Stepping On fall prevention program has been implemented throughout NSW since January 2009 but its impact on fall related health service use has not been investigated. This project aimed to use routinely collected information to document total and fall related health service use and costs following a fall requiring hospitalisation; and compare fall related health service use and costs in Stepping On participants pre and post program participation, with matched controls. Matched controls were selected from two different sources.

The CHeReL linked records from the Stepping On participant's data set to the NSW Admitted Patient Data Collection (APDC), the NSW Emergency

Department Data Collection, the NSW Ambulance Service Computer Aided Dispatch and Patient Health Care Record/Electronic Medical Record databases, plus death registrations from the NSW Registry of Births Deaths and Marriages, and ABS Mortality Statistics. The CHeReL also selected the two sets of matched controls; one set without dementia were selected from the NSW APDC, and the second set were community dwelling controls participating in the 45 and Up Study, who had previously reported a fall.

Fall related injuries in older people are a significant source of morbidity and health expenditure. The results from this project will provide information which will contribute to health service planning and strategies to better support older adults who are at risk of falls, particularly falls warranting hospitalisation.

Back to top

Epidemiology and outcomes of vascular surgery in older patients in New South Wales Associate Professor Vasi Naganathan, University of Sydney and Concord Hospital

Vascular diseases are more prevalent as people age; however often patients of very advanced age require vascular surgical intervention. Older patients having vascular surgery have a higher risk of adverse perioperative outcomes than younger patients, in particular higher overall mortality, more complications, increased reintervention and longer hospital stays. Strategies to improve perioperative outcomes in older people are hindered by limited evidence and prior to this project there was no published report outlining the outcomes of vascular surgical interventions in New South Wales hospitals.

This project aimed to provide a descriptive epidemiological overview of vascular surgery in NSW with a focus on older patients. Secondly using a cohort study design, the project aimed to investigate the impact of vascular surgery on patient centred outcomes such as discharge destination, length of stay, rehabilitation requirements, use of community services, repeat surgery and unscheduled readmissions, and mortality; and from there identify modifiable factors that would be amenable to quality improvement initiatives. Finally it sought to establish the impact of the structure and provision of health care services on patient outcomes following vascular surgery.

To facilitate this project the CHeReL linked records from the NSW Admitted Patient Data Collection, the NSW Registry of Births Deaths and Marriages death registrations, and the ABS Mortality Data. Study findings will feed into quality improvement initiatives to improve outcomes for older patients undergoing vascular surgery.

Back to top

Wealth and health in children and adolescents with chronic kidney disease. Dr Germaine Wong, University of Sydney

Children with chronic kidney disease (CKD) have a significantly greater health burden in terms of physical, psychosocial, cognitive and emotional wellbeing. Children with CKD are at risk of dying prematurely and those on dialysis have a significant disruption to their daily routine and quality of life. CKD impacts on child development and educational attainment and also results in a significant financial burden on the family. For poorer families, the financial burden compounds the health and development impact of CKD, resulting in worse outcomes for these children.

This project proposed to investigate the impact of CKD on school aged children and adolescents and their families, by estimating the prevalence of economic hardship amongst caregivers; determining the relationships between socioeconomic status and health, education and cognitive outcomes; investigating the impact of wealth on long term health and health related quality of life outcomes; and also describing the caregivers perspective on the financial impact of caring for children with CKD.

Children and adolescents aged 6-18 years with CKD and their carers were first surveyed to collect demographic, socioeconomic, health and education information. The CHeReL linked these records to the National Assessment Program – Literacy and Numeracy data, the Australian and New Zealand Dialysis and Transplant Registry, plus records from the NSW Admitted Patient Collection, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and the ABS Mortality Data and NSW RBDM death data.

Understanding and recognising the needs, of children with CKD is vital to ensure adequate provision of services. Understanding the needs of children with CKD from socially and financially disadvantaged families is particularly important to ensure equitable service and budget planning. It is envisaged that findings from this study will inform the development of strategies to provide much needed support for school aged children with chronic kidney disease.

Back to top

Demand for Emergency Service Trends in Years 2010-15 (DESTINY10.15): A population-based study of Emergency Department utilisation and length of stay in New South Wales Associate Professor Michael Dinh, Royal Prince Alfred Hospital

With demands for emergency department (ED) care increasing across Australia, managing access and demand, often in the absence of additional resources,

remains one of the fundamental challenges of modern emergency medicine. There is some evidence that there is a disproportionate increase in population based rates of ED care for those aged 80 years and over but the reasons underlying presentation are not well understood. Therefore an understanding of the increased demand on ED services at a population level will support better choices in the allocation of health resources and provide a basis on which to develop best practice models of care.

This study sought to understand the drivers of increased demand for ED services in NSW, focusing on the elderly and injury related presentations. Outcomes of interest include ED presentation and re-presentation rates, ED length of stay and admission rates for specific conditions, plus predictors of prolonged ED length of stay and ED re-presentation.

The CHeReL extracted all patient records from the NSW Emergency Department Data Collection for the years 2010-2015 from the Master Linkage Key. Findings from this project will facilitate ED resource planning to meet the future needs of emergency department patients.

Back to top

Single Practice, Multiple Hospital Review of Treated Aortic Aneurysms from 1987-2014 Dr Raymond Englund, R and R Englund Pty Ltd.

This retrospective practice audit uses linked data to ascertain short and long term outcomes following surgery for Abdominal Aortic Aneurysm repair. The audit spans almost 30 years, during which time the management of abdominal aortic aneurysm disease has changed significantly from open surgery to endovascular aortic aneurysm repairs.

Essentially the key outcome from aortic aneurysm surgery is duration of survival. The CHeReL linked a clinical practice registry to the ABS Mortality Data and NSW Registry of Births Deaths and Marriages death data. This linkage will enable complete follow up of all patients treated during the time period for accurate survival calculations and also facilitate individual quality control for the surgical practice of interest.

Back to top

Pathways of Care: a longitudinal study of children and young people in out of home care Ms Marilyn Chilvers, NSW Family and Community Services

Children in out-of-home care (OOHC) are at greater risk of negative outcomes than their peers in the general population, and are more likely to come into contact with the juvenile justice system and have poorer educational and health outcomes. The NSW Family and Community Services (FACS) have established a large scale prospective longitudinal study to examine the impact of OOHC on

children and young people who entered OOHC on a Children's Court order for the first time between May 2010 and October 2011. The study is examining family characteristics, child protection history, trajectories through care, and development and wellbeing during and after OOHC by in-depth interviews with children and carers, on-line surveys caseworkers and teachers and FACS administrative data. This project was extended to incorporate record linkage to health, education and criminal justice data.

To facilitate these additional objectives the CHeReL linked the Pathways of Care Longitudinal Study (POCLS) data to the Re-offending dataset (ROD) from the Bureau of Crime Statistics Research (BOCSAR), the Australian Early Development Census (AEDC), NSW National Assessment Program – Literacy and Numeracy scores, and the NSW Department of FACS Case Management System (KiDS). From the CHeReL Master Linkage Key, data from the NSW Admitted Patient Data Collection, NSWRBDM death data, ABS Mortality data, NSW Perinatal Data Collection, NSW Emergency Department Data Collection, and the NSW Mental Health Ambulatory Data Collection were linked to the POCLS data.

Record linkage has enabled development of a large, rich data resource which provides an opportunity to investigate outcomes for these children that would not have otherwise been possible. In particular, the addition of health, justice and educational data provides the opportunity to identify the predictors of outcomes such as mental health issues, injuries, poor academic achievement, criminal activity and re-offending. This project will add valuable information to the evidence base underpinning the justification for placing children in care and inform policy and practice for OOHC programs.

Back to top

Effects of opioid substitution therapy on health service use of people with opioid use disorders Dr Sarah Larney, National Drug and Alcohol Research Centre, University of New South Wales

People with an opioid use disorder (OUD) have complex health needs including higher rates of acute and chronic diseases. Recently, as this population ages, increases in cancer and chronic liver disease are being observed, raising questions about health service utilisation of people with an OUD and the extent to which pharmacotherapy for opioid dependence may impact health services use.

This project is investigating the impact of pharmacotherapy on health services utilisation. In particular it aims to investigate differences in health service use in people with and without opioid disorders and the impact of opioid substitution therapy on health service use and costs in people with an OUD.

The project is designed as a case control study. To establish the base cohort, the CHeReL linked data from the NSW Pharmaceutical Drugs of Addiction System (PHDAS), the NSW Emergency Department Data Collection (EDDC) and the NSW Admitted Patient Data Collection (APDC). The CHeReL also established two comparison control groups, by identifying matched non-OUD controls from the APDC and the EDDC. Two controls per case were identified, matched on case sex, age of case at the index opioid event and year of index opioid event. Identifying details from the cohort were provided to the Australian Institute of Health and Welfare to undertake a linkage to the National Death Index.

This project provides a unique opportunity to measure the burden of opioid use on health services, and through comparison with non OUD peers, identify those diagnoses with excess health service use. In turn this will inform programs for early intervention at the primary care level.

Back to top

Health service use in the older person with complex health needs: 45 and Up Study Mr Mark Bartlett, Sax Institute

People with complex health needs typically have multiple chronic conditions, frequent hospitalisations, and limitations on their ability to perform basic daily functions (due to physical, mental and psychosocial challenges). Effective healthcare for older people with complex health needs, their carers and families, requires a diverse range of health care professionals working together and services must be co-ordinated through a shared plan with joint accountability.

This project sought to inform the implementation and evaluation of the 'NSW Strategic Framework for Integrated care of the older person with complex health needs'. Baseline information on the current service use environment in terms of how and when older people access services, what type of services they access, and the nature and quality of communication between services was the key focus of this project.

A cohort of people selected from the 45 and Up Study aged 65 years and over formed the base cohort. This data set also includes Department of Human Services data from the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS). The CHeReL linked these records to the NSW Admitted Patient Data Collection, NSW RBDM death data, and NSW Emergency Department Data Collection. The study cohort comprised of people who were admitted to a NSW hospital with a primary or additional diagnosis indicative of 'geriatric syndrome' during the study period. A comparative control group with diagnoses other than geriatric syndrome conditions was also identified, thereby enabling comparisons between the study group and the group without geriatric syndrome.

In addition to supporting the implementation and evaluation of the 'NSW Strategic Framework for Integrated care of the older person with complex

health needs' findings from the study will inform initiatives to improve service co-ordination, and therefore health and wellbeing, for older people (as well as their carers and their families) with complex care needs.

Back to top

Health service use among NSW Workers (aged 45 and over) with chronic illness and life risks Mr Mark Bartlett, Sax Institute

Chronic diseases and related lifestyle risk factors lead to significant morbidity and associated health service usage and cost. Health service use associated with cardiovascular disease and diabetes in particular is significant.

The workplace is acknowledged as an important setting for health promotion interventions, and as such this project aimed to investigate health service use among NSW workers (aged 45 years and over) who have a newly acquired chronic illness or lifestyle risk, with a view to providing insight into the utility of the NSW workplace as a venue for disease and risk preventive interventions.

With cardiovascular disease (heart disease, stroke, hypertension, blood clots), diabetes, and obesity as the focus, this study aimed to describe the pattern of health service utilisation amongst working adults with a recently diagnosed lifestyle related chronic disease or the onset of obesity. The study also aimed to compare health service utilisation in this group with a comparison group without lifestyle related chronic disease or obesity; and estimate the differential cost of these conditions to the health system.

Working adults aged 45 and over with no pre-existing disease/risks were selected from the 45 and Up Study baseline survey. Risk and incident disease status at follow up identified those with or without a recently developed disease/risk factor. The CHeReL linked these records to the NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, and the NSW RBDM death data.

Department of Human Services data from the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS), available from the 45 and Up Study, were also used in the analyses.

Study outcomes will contribute to knowledge of the health services impact of a newly diagnosed chronic illness or recently acquire lifestyle risk in NSW workers, and will highlight opportunities for implementing disease and risk preventive interventions in NSW workplaces.

Back to top

BreastScreen NSW and 45 & up study data linkage Dr Anna Cohen, Cancer Institute NSW

BreastScreen NSW (as part of BreastScreen Australia) provides free screening every two years to women aged 40 to 74 years, while specifically targeting women aged 50-69. Studies have shown that with sufficient participation, mammography screening can substantially reduce mortality from breast cancer. As such, BreastScreen Australia has set a target participation rate of 70%.

It is widely recognised that a proportion of eligible women in the target age range are screened outside the BreastScreen program. For example through diagnostic imaging services funded through Medicare, or privately. The extent of out-of-program screening was last estimated in 2005; the purpose of this study, therefore, is to accurately quantify the number of women aged 50-69 years who are having Medicare reimbursed mammography for screening purposes.

The aim of this project is to estimate the 'true' BreastScreen participation rate across public and private screening sectors in NSW, and to describe the demographic profiles, screening patterns, interval cancer rate and mortality rates of women screened in BreastScreen and out of program.

Women participating in the 45 and Up Study formed the cohort for this study. The CHeReL linked the 45 and Up records to the BreastScreen NSW data, NSW Central Cancer Registry, NSW Admitted Patient Data Collection and the NSW RBDM death data. Relevant Department of Human Services Medicare Benefits Schedule records, available from the 45 and Up Study, were also obtained for each participant. This data linkage provided BreastScreen NSW with the opportunity to report against demographic information such as socio-demographic, cultural, health status, family health history, and living dependence attributes for the first time.

This study provides the opportunity to understand the level of need for BreastScreen services across NSW and to accurately monitor and report BreastScreen service performance. An understanding of the current service use patterns will enable targeted recruitment initiatives and relevant service provision into the future.

Back to top

Exploration of failure to access prescribed pharmaceuticals for people with chronic illness Dr Ian McRae, Australian Primary Health Care Research Institute, Australian National University

There is evidence, in Australia and overseas, that despite subsidised medicine schemes many patients find the cost of medicines prohibitive, leading to deferring or avoiding having prescriptions filled, or to substitution of medicines. Up to 14% of people with no financial stress, and 23% with financial stress defer or avoid filling prescriptions due to cost. With the cost of other essentials such as electricity increasing in excess of inflation many senior Australian households defer or delay spending on medical costs. Increases in

prescription co-payment charges have also been associated with a reduction in the proportion of prescriptions dispensed. Other factors that feed into decision making about medications include the severity of symptoms, medicine effectiveness, and the necessity of treatment.

This project aims to explore the issues of use and failure to use pharmaceuticals using respondents in the 45 and Up Study. The specific aims are to describe patterns of purchasing of prescription and over the counter drugs based on demographic, financial and health characteristics; and describe the characteristics of patients with chronic illnesses who are not accessing prescribed prescription drugs. A separate study using qualitative methods will explore the decisions not to purchase medications for short term events to broaden the scope of the project.

The project uses the 45 and Up Study survey data linked to Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data, with these records linked by the CHeReL to the NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, and NSW Registry of Births Deaths and Marriages death registrations. Findings from this project will provide a strong basis for exploring the issues related to purchasing of medications in the qualitative studies.

Back to top

Relationship of socioeconomic status to health services use Professor Emily Banks, Australian National University

The association between socioeconomic disadvantage and mortality and morbidity is well established. Consequently the overall burden of health service use is also likely to be considerably greater in those who are more disadvantaged. Nevertheless there is little information on the burden of health service use in Australia associated with socioeconomic disadvantage. The extent of equal care for equal need is also not evident – despite having a universal health care system, the socioeconomically disadvantaged possibly derive less benefit from the system due to the public/private funding mix; out of pocket expenses and gaps in services.

This project aims to describe the burden of hospitalisation in terms of rates and costs, in relation to socioeconomic status; and to quantify socioeconomic inequalities specifically for hip and knee replacement surgery, adjusting for ‘need’. Findings on inequalities in hospitalisations will demonstrate the benefits to society in reducing socioeconomic inequalities and relieving the burden on hospitalisations. Need adjusted inequalities for knee and hip surgery will help to highlight avoidable sources of inequality which can inform policies and initiatives to improve equity of access in health care.

Back to top

Social interaction, psychosocial and life distress, cardiovascular and stroke morbidity and all-cause mortality Dr Philayrath Phongsavan, Prevention Research Collaboration, University of Sydney

Social relationships are critical for maintaining health and well-being. Individuals with stronger social relationships have an increased likelihood of survival compared to those with weaker relationships; conversely social isolation is associated with increased all-cause mortality, cardiovascular disease and psychological distress. However what is not clear is whether social isolation and psychological distress independently contribute to mortality, or if psychological distress amplifies the effect of social isolation on mortality. Furthermore stressful life events can act as a trigger for a cardiovascular event and a risk factor for mortality; but it is not clear whether people who experience stressful life events but are more socially connected have a lower risk of morbidity and mortality.

This project aims to examine the role of social interaction or isolation and psychological and life event distress in predicting cardiovascular and stroke morbidity and all-cause mortality, and the interaction between these factors. It will also examine if social interaction moderates the effects of psychosocial and life event distress on mortality and morbidity, or confers any positive effects on health regardless of psychosocial and life event distress.

Findings from the study will have important policy implications for informing public efforts to reduce social isolation in order to minimise the risk of premature morbidity and mortality.

Back to top

Cervical cerclage in NSW: trends, risk factors and outcomes Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

Preterm birth prior to 37 weeks gestation complicates approximately 8% of pregnancies in NSW and is a major cause of perinatal mortality and morbidity. Cervical cerclage is a surgical procedure where a suture is placed around or above the cervix in an attempt to prevent cervical dilation or shortening, used to prevent preterm birth. The timing of insertion is unknown in Australian maternity populations; as is the proportion of women who have a second trimester loss or go on to have a birth ≥20 weeks gestation. Although cervical cerclage reduces the incidence of recurrent pre-term birth in women at risk, uncertainty exists about who is at high risk, how to treat them, and the long term impact of cerclage on the baby. In addition cervical cerclage carries a number of risks for the woman and baby.

This project aims to describe the patterns of use of cervical cerclage and the maternal health, reproductive history and pregnancy characteristics of women undergoing it; describe the range of services where cerclage procedures are performed; assess trends over time in first time use of cerclage; and describe pregnancy outcomes by gestational age at insertion. A control group of women at high risk of miscarriage or preterm birth who did not have cerclage will provide a comparison group. The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets linked by the CHeReL used in this study were the NSW Admitted Patient Data Collection; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; and the NSW Perinatal Death Reviews.

This study will provide information on the use and outcomes of this procedure, in particular the probability of the fetus reaching a viable gestation age. If there is evidence of overall benefits from cerclage, it may be possible to identify pregnancy subgroups where the benefits are more likely. This will improve the quality of information available to couples and their health care providers and potentially reduce the number of very preterm infants

Back to top

Costs and benefits of prevention: Implications on the distribution of health Professor Louisa Jorm, University of Western Sydney

Over the next 30 years chronic conditions will impose an increasing burden on the population in terms of health and disability status, and use of and cost to health services. Prevention has the potential to make a significant contribution to improving health outcomes and health related quality of life, reducing health inequalities and minimising unnecessary demand for health care services. However the issue of how much preventive intervention can improve the distribution of health has not been studied quantitatively. Therefore the aim of this study is to develop a predictive model of the long term trajectory of the population in terms of health conditions, health service use and expenditure. Using scenario modelling, the effects of preventive policies will be explored by creating appropriate counterfactual scenarios for various chronic health conditions, risk factors and socioeconomic and geographic inequalities to model the changes under each set of conditions.

This project will provide a visualisation of the future trajectory of the population and will identify factors to take into account when designing prevention programs. It will also help clarify the role that prevention can play in reducing health inequalities.

Back to top

Long term health outcomes in people with HIV followed since seroconversion. Primary HIV Infection linkage study Professor

Anthony Kelleher, The Kirby Institute, University of New South Wales

The global public health impact of HIV is significant with more than 30 million people infected worldwide. Whilst there is no cure, the development of combination antiretroviral therapy now means that, in developed countries at least, HIV/AIDS is a chronic treatable condition. However, the increased longevity brings with it increased morbidity for people living with HIV, with evidence of early onset cardio and cerebrovascular diseases, liver and renal disease.

The Primary HIV Combined Database (PCUD) is a large cohort of people from NSW and Melbourne with primary HIV infection who have been followed from as early as 1983. Data collected includes blood samples for viral load and Tcell counts, plus information on treatment and disease progression. This cohort provides a rich source of information with which to examine the natural history of infection and how it has changed over time, examine interactions between disease, ageing and co-morbidities, determine clinical outcomes, and explore trends in mortality over time.

The capacity for linkage to additional administrative data sets provides an opportunity to further enhance the value of the PCUD cohort. Using NSW cases on PCUD as the cohort, the CHeReL linked records from the NSW Admitted Patient Collection, NSW Emergency Department Data Collection, NSW Cancer Registry, NSW Notifiable Conditions Information System plus the ABS Mortality Data and NSW RBDM death data.

As more and more people are living with HIV, an understanding of disease progression and outcomes and the impact of long term therapy will provide valuable evidence to support those both providing and receiving treatment. Importantly results can be used to maintain the public dialogue about the prevention and treatment of HIV.

Back to top

Health outcomes in gay men: HIM and pH data linkage study Dr Janaki Amin, The University of New South Wales

Gay men comprise a significant minority of the Australian male population and the vast majority of the Australian HIV positive population. Very little data has been systematically collected about the determinants and long term health of gay men in comparison to the general population and no comparisons have been made in this regard between HIV positive and negative gay men. This project will use data linkage to routinely collected health databases to identify health outcomes in the Health in Men (HIM HIV negative) and Positive Health (pH HIV positive) cohorts. Data sets that will be linked include accident and emergency attendance, hospital admissions, notifiable diseases, cancer and

death registers. This project will help identify the specific health needs of gay men. Further, the project will aim to examine determinants of health outcomes, particularly mental health outcomes. These findings will be fed back to community organisations to provide an evidence base on which to build policy responses.

Back to top

Transitioning from hospital to home: Effectiveness of occupational therapy home visit discharge planning program for at risk older adults Professor Lindy Clemson, University of Sydney

Occupational therapy assessments conducted before discharge with at-risk older people aim to enable safe independent transition from hospital to home. Previous research shows how potentially serious problems identified on home visits with the client were not identified in hospital consultations. This study aims to determine the clinical and cost effectiveness of a comprehensive occupational therapy discharge planning intervention which is primarily conducted in the home and is thus contextually relevant and tailored for individual need.

The primary aim of this study is to determine if people who receive the HOME intervention will have: higher levels of functional independence than the control group, and higher levels of participation and resumption of usual life activities compared to the control group. The secondary aim is to determine if the HOME intervention will: i) improve older people's self-efficacy for carrying out activities of daily living at home and in the community, as well as physical activity and health-related quality of life to a greater degree than the control group; (ii) reduce falls; and (iii) examine if baseline characteristics of participants (age, gender, co-morbidities) are predicative of differential effects of intervention. Additionally, the study will determine the cost effectiveness of the HOME intervention.

The HOME intervention is a randomised controlled trial of occupational therapy discharge planning compared to an occupational therapy in-hospital consultation. The primary end-point was 3 months post-discharge, with a 12 month follow up via phone call to participants to record aspects of functional independence. Follow up through data linkage occurred via the CHeReL of HOME trial participants to NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, and NSW Registry of Births Deaths and Marriages death registrations.

Back to top

Epidemiology and Management of Solid Organ Injury (SOI) (Liver, Spleen, Kidney, Pancreas) in Individuals Aged 0-25 in NSW Remote, Regional and

Metropolitan Non-Trauma Centres and Metropolitan Trauma Centres, Adult and Paediatric Dr Susan Adams, Sydney Children's Hospital

Injury is the leading cause of death in children over the age of 1 and continues up to the age of 40. Prevention remains key to reducing paediatric trauma deaths. In order to devise relevant preventative strategies, an understanding of the epidemiology is essential. Given that injuries will still occur, effort is also needed in the "control" of injury – that is improving the patient outcome once injury has occurred. This requires focus on the quality of care from the pre-hospital setting through a local or regional hospital and on to the paediatric trauma centre (PTC), to prevent injury mortality and reduce morbidity.

This project aims to:

- To describe the pattern of Solid Organ Injury (SOI) across NSW in children and young people by geographical region, gender, age group, external cause, place of occurrence, ethnicity and indigenous status
- To determine if the management of solid organ injury (spleen, liver, kidney, pancreas) between the ages of 0-25 differs according to the designation of the hospital to which the patient is admitted and managed.

A cohort of patients from the NSW Admitted Patient Data Collection with a trauma admission aged 0-25 at the time of admission with a diagnosis for solid organ injury for the period 1 July 2000 and 30 September 2011 was linked to other records from the NSW Admitted Patient Data Collection, NSW Registry of Births Deaths and Marriages death registrations and ABS Mortality Data Collection.

Back to top

The burden and cost of injury attributable health care use and mortality in Australia Associate Professor Rebecca Mitchell, Australian Institute for Health Innovation, Macquarie University

This project was conducted for the Population Health Research Network (PHRN) as one of the proof of concept projects for national data linkage. The project broadly aimed to describe the health care use and mortality of injured people in Australia and to quantify the extent to which these outcomes can be attributed to their injury. The project had both logistical and epidemiological aims, including (1) to identify an injured (via an index hospital admission) and non-injured (randomly selected via electoral rolls) cohort matched on age group, gender and area of residence; (2) to detect the extent of any cross jurisdictional border use of health care facilities (i.e. ED presentations and/or hospital admissions) for each cohort; (3) to describe health care use (in terms of ED presentations and/or hospital admissions) of injured and non-injured

cohorts; (4) to describe the cause and incidence of mortality in the injured cohort and matched non-injured cohort (1 year post the date of injury); and (5) to quantify the morbidity and mortality attributable to the index injury by comparing health care use of the injured and non-injured cohort (controlling for pre-injury health service use).

The injured cohort were selected using ICD-10 codes from the NSW Admitted Patient Data Collection (APDC). The non-injured cohort were randomly selected from the NSW Electoral Roll matched by age group, gender and postcode. Linked records from the APDC, NSW Emergency Department Data Collection (EDDC) and NSW RBDM death registrations for the injured and non-injured cohort were extracted from the Master Linkage Key by the CHeReL. National Data Linkage was conducted by the National Centre for Data Linkage (CDL).

This research will contribute to informing worldwide research efforts on injury-related disability and comorbidity. In addition, the research will demonstrate the feasibility of cross-jurisdictional data linkage using the PHRN, enabling existing health data from around Australia to be brought together and made available for health and health-related research purposes.

Back to top

Long-term outcomes of testicular and germ cell tumour patients in Western Sydney (GCT Outcomes Study) Associate Professor Howard Gurney, Westmead Hospital

There is little Australian data examining the long-term outcomes in patients with testicular and germ cell tumours (GCT) and it is well established that treatment of these cancers within a centre of excellence is associated with better survival. Testicular cancer patients are commonly young individuals who require multiple treatment modalities, including surgery, chemotherapy and radiotherapy, with a curative intent. Examining the survival outcomes, prognostic factors, patterns of care, long-term toxicity and survivorship issues in this group of individuals within this major cancer network will be valuable for international comparison and to provide a benchmark for other Australian centres.

The primary objective of the study is to evaluate the long-term outcomes of testicular and GCTpatients, including overall survival and long-term toxicity, such as second malignancy, cardiovascular events and infertility. Secondary study objectives include assessing patterns of care, patterns of relapse including prognostic factors and relapse-free survival, progression-free survival after treatment, acute and other long-term toxicity of treatment, factors that correlate with specific long-term treatment adverse events and survivorship issues. This is an observational clinical study of patients with testicular and germ cell cancers diagnosed and/or treated between the 1st January 1990 and 31st December 2010 in the Sydney West Cancer Network. A retrospective analysis of the GCT Outcomes Study Patient Information data was conducted via data

linkage to the NSW Registry of Births Deaths and Marriages death registrations, ABS Mortality data collection and NSW Cancer Central Registry.

2013

Back to top

Comprehensive linkage of population data for perinatal research Associate Professor Christine Roberts, the Kolling Institute, University of Sydney

The following projects constitute a program of work to establish an Australian birth cohort and investigate patterns and trends in maternal and child health, health care utilisation, and development. The birth cohort comprises all women with a hospitalisation, those giving birth and their infants born in NSW and the ACT from 1994-2015 with follow up until the child's tenth birthday. The Projects involve analysis of population-based record linked laboratory, birth, hospital, newborn screening, pharmaceutical, education and death data. The CHeReL linked data from the Pacific Laboratory Medicine Service (PaLMs); the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection; the NSW Newborn Screening Programme; the NSW Pharmaceutical drugs of addiction system; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews; the Australian Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

Back to top

Health and wellbeing of people with intellectual and developmental disabilities within NSW Professor Julian Trollor, University of NSW

The following projects constitute a program of work to investigate the health and mental health services used by people with an intellectual disability. People with Intellectual Disability (ID) have increased rates of mental illness compared to the rest of the population. These increased rates of mental illness apply to most common mental disorders and are evident in children, young people and adults.

Data linkage affords the ideal opportunity to build an epidemiological profile of this population group, as information on intellectual disability is not collected in a structured way that informs service and policy development and delivery. The CHeReL linked data from the following collections for this project: links the Disability Services Minimum Dataset (DS-MDS) held by Ageing, Disability & Home Care (ADHC) at NSW Department of Family & Community Services, the NSW Admitted Patient Data Collection, the NSW Mental Health Ambulatory Data Collection, the NSW Emergency Department Data Collection, the NSW

RBDM death registrations and the Cause of Death Unit Record File, data from NSW Department of Education, NSW Public Guardian and NSW Ombudsman data collections, and Statewide Disability Services data from Corrective Services.

This linkage will enable the investigation of co-occurring mental illness, patterns of service delivery and service pathways for people with an intellectual disability and health outcomes compared with the general population.

Back to top

Evaluation of the Medicare Service Incentive Payments for Asthma and Diabetes Professor Jane Hall, CHERE, University of Technology

This project seeks to examine the impact of the Practice Incentive Program and the Service Incentive Program (SIP) on the quality of primary care in Australia for people with specified chronic health conditions, namely asthma and diabetes. Globally many incentive schemes to influence GP behaviour and improve access and affordability of care have been introduced, and an increasing number of studies have sought to evaluate changes in GP behaviour and quality of care arising from these schemes. However the evidence has largely been inconclusive with effects ranging from negative to very positive, and most reviews conclude that more research is needed. Australian evidence on the effects of pay for performance incentives is limited and has also been inconclusive.

The overall aim of this project is to understand what impact the asthma and diabetes SIPs have had on health, health care utilisation and associated costs. In particular it will describe the patterns of use of the asthma and diabetes SIPs, including characteristics of patients who do and do not have claims; examine changes in use of health services and costs of health care for individuals before and after a SIP claim; and compare health service use for people with asthma and diabetes who do not have a SIP claim. For this project the 45 and Up Study survey data linked to Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data were used, with these records linked by the CHeReL to the NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, and NSW Registry of Births Deaths and Marriages death registrations.

This project will provide insight into the value and utilisation of financial incentives and their effectiveness in improving accessibility of care and the relationship between primary care and the broader health system. Ultimately this will inform future funding mechanisms, in turn improving primary care services, patient outcomes and health service efficiency.

Back to top

Evaluating appropriate use of blood products in mothers and babies Associate Professor Jane Ford, The University of Sydney

As a limited and costly resource, it is important that blood products are used judiciously. Blood transfusions associated with childbirth are increasing, while there is concern regarding potential adverse outcomes post-transfusion. There is likely variation in practice in the use of blood products, amount transfused and haemoglobin thresholds for transfusion at childbirth. Current monitoring of blood product use does not track patient outcomes post-transfusion.

This project aims to improve the safety and appropriate use of blood and blood products during pregnancy, childbirth and the newborn period. Record linkage of existing patient level population data (NSW Perinatal Data Collection, NSW Admitted Patient Data Collection, NSW Registry of Births Deaths and Marriages death registrations, NSW Perinatal Death Review, ABS Mortality Data, ABSPerinatal Mortality and Neonatal Intensive Care Unit Study) to CEC Red Cell Utilisation data (Blood bank & Pathology) and Australian Red Cross Blood Services will be used to address these aims. Researchers will investigate adverse outcomes of maternal and infant transfusion with particular focus on timing, type of product, amount transfused, age of blood and morbidity following transfusion. Variation in practice will be compared across hospitals and inform a separate audit.

Back to top

Bulk billing and out of pocket costs since the introduction of the 'Strengthening Medicare' policy Professor Jane Hall, CHERE, University of Technology

This project seeks to examine the affordability of GP services and the impact of the 'Strengthening Medicare' policy introduced in 2004 which provided financial incentives for GP's to bulk bill children, health care card holders and people living in rural and remote areas. Since the introduction of this policy the rate of bulk billing has shown a sustained increase, although it is difficult to separate this from the general upward trend in the number of services for all un-referred attendances. In addition, there has been little attempt to assess the policy impact of this initiative, and much of the work that has been done focuses on the proportion of services bulk billed rather than patients. There has also been little work done on the health care needs of patients who are or are not receiving bulk billed services and the extent to which the reforms have improved the affordability of GP services in areas of need targeted by the Strengthening Medicare policy.

This project aims to investigate the impact of the Strengthening Medicare policy. Specifically it will describe bulk billing practices and incentive claims over the five years since the policy was introduced, including numbers and characteristics of people receiving bulk billed services; the proportion of GP services which are bulk billed; regional characteristics of GP location; associations between bulk billed services and non-urgent emergency department attendance and the extent to which these vary over the five years; and describe utilisation and costs of other ambulatory care services and the contribution of GP services to overall out of pocket costs. For this project the 45

and Up Study survey data linked to Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data were used, with these records linked by the CHeReL to the NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, and NSW Registry of Births Deaths and Marriages death registrations.

This project will provide insight into the value and utilisation of financial incentives and their effectiveness in improving accessibility of care and the relationship between primary care and the broader health system. Ultimately this will inform future funding mechanisms, in turn improving primary care services, patient outcomes and health service efficiency.

Back to top

Health service utilisation before and after a diagnosis of cancer: a data linkage study using the 45 and Up Study cohort Ms Deborah Baker, Cancer Institute New South Wales

People diagnosed with cancer will have contact with a wide range of health care services in the time leading up to, and following, their cancer diagnosis. This study aims to quantify health service use in a cohort of people with cancer in NSW, and to describe patterns of use of primary and specialist consultations and diagnostic tests. This information will be used to inform future initiatives to streamline care pathways and improve cancer care services outside of hospital settings.

A cohort of people in the 45 and Up Study and people aged 45 years and above at cancer diagnosis recorded in the NSW Central Cancer Registry between February 2006 and December 2009 was linked by the CHeReL to all other records in the NSW Central Cancer Registry, NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, NSW Registry of Births Deaths and Marriages death registrations and ABS morality data collection. Medicare Benefits Schedule treatment data and Pharmaceutical Benefits Schedule cancer-related systemic therapy data were provided via the 45 and Up Study.

Back to top

Hospitalisations By Oldest Old People And Those Who Have Had Stroke In The 45 And Up Study Prof Julie Byles, The University of Newcastle

Older people are admitted to acute hospitals more commonly and have longer lengths of stay than younger persons. This project will use linked data from the 45 and Up Study, NSW Admitted Patient Data Collection and NSW Registry of Births, Deaths and Marriages to develop understanding of patterns and pathways of hospital services as people age. By linking longitudinal survey data

with health services data it is possible to determine individual factors associated with use of these services as people age. Findings will indicate which inpatient hospital services are most used by an increasingly older population, what types of services are associated with increased health and decreased need. We will also particularly focus on hospital services and health outcomes for those who have experienced a stroke. This project will allow better health care and service planning for the health needs of the older residents in the NSW community.

Back to top

Study of inpatient and outpatient care following a suicide attempt Dr Matthew Spittal, The University of Melbourne

Internationally, relatively little is known about health care contacts following attempted suicide. What evidence there is suggests that the majority of those who presenting at emergency departments for self-harm are discharged to the community without referrals for follow-up care or have poor compliance with referrals for outpatient care.

This study will investigate patterns in the use of inpatient and outpatient mental health services among individuals who have been admitted to hospital for deliberate self-harm. Using linked hospital admission, mortality and mental health ambulatory data, the investigators will construct a cohort of individuals admitted to hospital for self-harm. They will then examine the occurrence of four key outcomes among this cohort: all-cause mortality; suicide mortality; re-admission to hospital for deliberate self-harm within 30 days of the index episode; and use of mental health outpatient services within 30 days of the index episode. They will examine demographic and clinical factors that predict each of these outcomes.

Results from the study will inform strategies for the treatment of individuals who attempt suicide.

Back to top

Ongoing data linkage of Health datasets to CrashLink Mr Andrew Graham, NSW Centre for Road Safety

This is a population based record linkage study which proposes to link routinely collected state based health data collections (NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, NSW RDBM Death registrations, ABS Death NSW Deaths, ACT Admitted Patient Data Collection and ACT Emergency Department Information System) to the NSW Centre for Road Safety CrashLink system data (NSW crash reports from NSW Police Force). The cohort for this research project is from the NSW CrashLink system and includes all persons injured or killed due to road crashes that occur

on NSW classified and local roads from 1 January 2012 for NSW datasets or from July 2004 for ACT datasets.

The findings will enable identification and monitoring of the incidence of crash related serious injuries and augment CRS data to provide a more detailed picture of the outcomes of road traffic crashes. The collective data will enable planning and measurement of key strategic initiatives and road safety campaigns and provide evidence for both current and future policy and funding programs.

Back to top

Interval Colorectal Cancer after Colonoscopy in the ACT Dr Kavitha Subramaniam, The Canberra Hospital

Colorectal cancer (CRC) is a major public concern in Australia. Recent literature suggest that a proportion of patients may develop interval cancer; colorectal cancer after a colonoscopy that is negative for cancer. Based on a recent meta-analysis, approximately 1 in 27 CRCs are interval CRCs (Singh et al, 2014). There have been a number of clinical, procedural (including quality indicators) and biologic factors that have been identified with risk of developing interval CRC.

This retrospective population-based cohort study aims to determine the rate and the predictors and pathology of interval colorectal cancers in the ACT. Colorectal cancers detected in the ACT from 2001 – 2009 will be determined from the ACT Cancer Registry. All patients with a diagnosis of colorectal cancer from the ACT Registry was linked to the Gastroenterology Endoscopy Database and records corresponding to a colonoscopy have been examined and classified as ‘diagnosis of colorectal cancer made’ or ‘diagnosis of colorectal cancer not made’.

Back to top

The finance and economics of primary health care Professor Jane Hall, CHERE, University of Technology Sydney

There has long been interest in how primary care is financed, and how the incentives of different payment mechanisms influence the delivery of services. The effects of single payment mechanisms are reasonably well understood, and health systems around the world are exploring how to use blended payment systems to achieve better outcomes. There is a need to build the sort of evidence that can help develop effective policy in this important sector. This program of research will be conducted by the Centre for Research Excellence in the Finance and Economics of Primary Care.

There are three overarching aims of the program:

1) To evaluate the impact of existing financial incentives and changes in policy settings in Australia's primary health care system, on access, the subsequent utilisation and cost of health services.

2) To examine how health status, socio-economic resources and other factors such as rural and remote area of residence affect the use of primary health care.

3) To investigate the contribution of primary care to the overall performance of the health care system and the extent to which changes in funding arrangements in primary care impact on the utilisation of services in other sectors of the health system.

The project will consist of prospective and retrospective cohort studies that will link 45 and Up baseline survey data to administrative heath data sets. 45 and Up Study data was linked to the NSW Admitted Patients Data Collection, NSW Emergency Department Data Collection and NSW Registrar of Births Deaths and Marriages - death registrations; and to Medicare data (PBS and MBS). This research will better inform the design of primary care funding mechanisms in the future. Ultimately this could lead to better provision of primary care services, improved patient outcomes, and a more efficient use of health care resources for primary care.

Back to top

A contemporary population study on venous thromboembolism and its short and long-term impact on morbidity and mortality-collected data? Professor Leonard Kritharides and Dr Austin Ng, Concord Hospital, The University of Sydney

Venous thromboembolic (VTE) disease is a worldwide problem, with acute pulmonary embolism (PE) it's most severe manifestation. Studies have emerged showing that the increased mortality from an acute PE episode is not confined to the short-term. Long-term outcome studies showed increased 1-year mortality rate after PE may be as high as 25%. Increased long-term risks of recurrent PE, cancer and cardiovascular events have also been reported in patients presenting with acute PE. The investigators of this project believe there is a potentially greater unrecognised community risk associated with increasing use of percutaneous transvenous cardiac procedures and devices implantation.

The aims of the project are to:

- Investigate the morbidity and mortality outcomes for the study's single-centre cohort of patients following their confirmed acute PE.
- Investigate the prevalence of VTE (PE and/or DVT) in the state of NSW and its relationship to specific potential risk factors of interest.
- Investigate the incidence of non-fatal and fatal index and recurrent VTE according to baseline demographics and a history

of: VTE (PE and/or DVT), coronary disease, heart failure, stroke, atrial flutter/fibrillation and malignancy.
- Investigate the incidence of fatal cardiovascular disease, and hospitalisation for non-fatal coronary disease.

This population linkage study used records from the Concord Hospital Pulmonary Embolism data collection, NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, NSW Registry of Births, Deaths and Marriages death registrations and ABS mortality datasets. This study will provide contemporary insights into the outcome of patients with VTE, identify those that are at high risk of death during follow-up, and define the VTE risk of commonly performed invasive cardiac procedures.

Back to top

Injury-related hospitalisations in people with dementia - causes, consequences and costs Dr Lara Harvey, Neuroscience Research Australia

People with dementia have been shown to have much higher hospitalisation rates than those without dementia. However, no in-depth examination has been conducted that has examined all injuries by injury mechanism and whether dementia sufferers experience a different injury profile compared to individuals without dementia, nor whether health outcomes of individuals with dementia are worse for all types of injuries. This study aims to examine hospitalisations for patients with dementia who were admitted to a NSW hospital for an injury or poisoning during the ten year period 2002 to 2012. The investigators aim to examine the injury and poisoning profile of people with dementia in NSW hospitals and determine if the health outcomes for elderly people admitted to hospital for an injury and poisoning differ between those with and those without dementia. This is a population-based retrospective cohort study of all people aged 50 years and older, resident in NSW, with an admission to hospital between 1 January 2002 to 31 December 2012, and a principal diagnosis of injury. The CHeReL linked records of the NSW Admitted Patients Data Collection with NSW RBDM death registrations and ABS mortality data collection.

This research will provide much needed data on the impact of injury on the person with dementia by providing an in-depth profile of injury related hospitalisation in people with dementia and by exploring the impact of increasing incidence and prevalence of dementia on patterns of injury over time. This information will be used to identify priority areas for research as well as inform and influence policy and planning in this area in NSW and beyond.

Back to top

Birthplace in Australia Professor Caroline Homer, University of Technology, Sydney

The places of birth available to women in Australia are standard hospital labour wards, birth centres attached to larger obstetric units, stand-alone midwifery units (geographically separate from the hospital labour ward) and birth at home. More than 7,500 babies are born outside standard labour wards in Australia each year. However, there is limited evidence for the safety of these alternative settings, and significant concerns have been raised about their safety particularly for babies. This study, the first study of its kind in Australia, will provide the evidence required by policy makers and service providers. The study will use routinely collected data from various Australian jurisdictions to investigate the impact of place of birth on neonatal and maternal outcomes.

The primary aim of this project is to compare neonatal morbidity and mortality associated with births that at the onset of labour are planned to be in one of three places - at home, in a birth centre or in a standard hospital labour ward. The secondary aims are: (1) to compare these groups on outcomes of interest (interventions during labour, maternal morbidity and mortality); (2) to explore outcomes for women and babies who planned to give birth at home or in a birth centre but required transfer to a higher level service during or after labour; and (3) to undertake a cost analysis of the three different sites for birth for both the birth process and the readmission costs.

This is a population-based cohort study using routinely collected linked data. Births were eligible for this study if: (a) they occurred between January 1st 2000 and December 31st 2012 as recorded in the NSW Perinatal Data Collection; and (b) woman who gave birth to a singleton baby in the cephalic presentation. In NSW, data from the NSW Perinatal Data Collection was linked to NSW Admitted Patient Data Collection, ACT Admitted Patient Data Collection, NSW Registrar of Births Deaths and Marriages death registration, and ABS mortality data collection.

Back to top

Intellectual Disability Mental Health Data Linkage Project Associate Professor Julian Trollor, University of New South Wales

Currently in NSW, there is limited data about people with an intellectual disability (ID) and the health and mental health services used by this population. Data on people with ID is not collected in a structured way that informs service and policy development and delivery.

This project aims to build an epidemiological profile of the health and mental health of people with ID in NSW by linking the Ageing, Disability & Home Care (ADHC) NSW Department of Family & Community Services Disability Services Minimum Dataset (DS-MDS) with datasets from the NSW Ministry of Health. These are the Admitted Patient Data Collection (APDC) and the Emergency Department Data Collection (EDDC). The project will also link the DS-MDS to the Mortality Data from the ABS and the Register of Births Deaths and Marriages (RBDM). The project will link retrospective data for the period 2005 – 2013. This

project intends to incorporate MH-AMB data collection in a future linkage update. The findings will establish an epidemiological profile of people with ID and mental illness, enabling identification and quantification of patterns of service delivery. This will lead to a better understanding of the service pathways engaged by this population between disability and health services. Numerous publications are currently underway.

Back to top

Mapping the outcomes of calls to 'healthdirect Australia' Professor Louisa Jorm, Centre for Big Data Research in Health, University of New South Wales

Healthdirect Australia provides, through contracted services, a telephone-based health care triage and advice service known as healthdirect Australia. This is a 24 hours a day, 7 days a week nurse triage service. Between 9-13% of callers are directed to attend an emergency department (ED) via private transport, while around 50% are directed to visit a general practitioner (GP) within a specific timeframe. The extent to which patients follow the advice of healthdirect Australia to visit a GP or attend an ED is unknown. Linkage of healthdirect Australia operational call data with routinely collected data about subsequent service use and outcomes offers the potential to evaluate the quality of these services on a whole-of-population basis, and in a timely and efficient way.

This observational cohort study seeks to address four main objectives: 1) Quantify the extent to which healthdirect Australia advice is being followed; 2) Describe patient outcomes (including ED presentations, hospital admissions, deaths) following calls to healthdirect Australia; 3) Identify the characteristics of patients (including demographics, geography, diagnoses) who are less likely to follow advice and/or who have unfavourable outcomes; and 4) Explore how features of healthdirect Australia service provision (including protocols used, who provided the advice, time of call) relate to 1) to 3). The study population includes all NSW and ACT residents who were the subject of calls to healthdirect Australia between 1 July 2008 and 31 December 2012. This cohort was linked by CHeReL to the NSW Admitted Patient Data Collection, ACT Admitted Patient Collection, NSW Emergency Department Data Collection, ACT Emergency Department Information System, NSW Registry of Births Deaths and Marriages death registrations, the 45 and Up Study data collection and ABS Mortality data collection. Medicare Benefits Schedule treatment data and Pharmaceutical Benefits Schedule cancer-related systemic therapy data were provided via the 45 and Up Study.

Back to top

Rehabilitation Outcomes of Patients Admitted After Road Trauma Associate Professor Steven Faux, St Vincent's Hospital

The focus of acute trauma care teams is to improve mortality and morbidity. Improved functional outcomes at discharge can only be achieved through early involvement of allied health and rehabilitation services. Although there is a smooth system of transfer to a trauma centre, rehabilitation services in these tertiary hospitals in Sydney currently have little spare capacity to accommodate the significant additional caseload. This then impacts on the progress of these patients as their journey from acute care bed to a rehabilitation bed is delayed. Transferring a patient from a tertiary hospital back to the local rehabilitation facility is often difficult with significant delays which results in acute bed block at the trauma services.

There has been no study of access to rehabilitation care for road trauma patients undertaken in Australia previously. Data is needed on the journey of road trauma patients from acute care to rehabilitation care to address several aspects of role of rehabilitation in trauma care. The overall aim of this project is to accurately and reproducibly examine acute care of trauma patients and link this data to the rehabilitation outcomes. It will identify factors that determine functional outcomes and length of stay. For this retrospective study, the CHeReL linked a cohort from the NSW Trauma Registry to the Australasian Rehabilitation Outcomes Centre (AROC) data collection.

Back to top

Using patient experiences of adverse events to improve health care delivery and practice Professor Merrilyn Walton, University of Sydney

Knowing how patients experience their health care is fundamental for effective service delivery yet the policies that underpin delivery systems are developed without evidence of patients' experiences of adverse events while in hospital. This research addresses this significant deficit by undertaking an investigation of the experience of adverse events amongst recently hospitalised patients in New South Wales. The study aims to investigate the experiences of patients who have suffered an adverse event in order to create more effective service and policy responses to adverse events.

This is a mixed methods study involving data linkage between the NSW Admitted Patient Data Collection, Registry of Births Deaths and Marriages death registrations and ABS mortality data collection and the 45 and Up Study via CHeReL. Linked data will be used to identify potential participants in the 45 and Up Study cohort who have been hospitalised during the most recent six months for which data is available. Individuals in the 45 and Up Study who have had a hospitalisation during the most recent six months will receive a study invitation. The respondents will then be divided into two groups: those who experienced an adverse event and those who did not (control group). The survey includes qualitative and quantitative methods. Patient experience of adverse events will be categorised using the WHO International Classification for Patient Safety. Quantitative methods will be used to identify the extent of adverse

events experienced by patients as well as isolate common features of that experience.

Back to top

Four resource levels and their association with cognitive decline Miss Lily O'Donoughue Jenkins, Australian National University

This project aims to examine the four varying levels of resources - individual resilience, social networks, primary care and tertiary care - and determine how each level is associated with the rate or risk of cognitive decline. For the first level the aim is to examine inner resources of resilience as well as personal resources that may be associated with resilience, such as diet or exercise, and whether these factors contribute to cognitive decline. The aim of the second level is to examine how individual's social engagement is related to cognitive decline and what specific aspects of social engagement is associated with cognitive decline. The third level aims to analyse the correlation between frequency of primary care use and cognitive decline and analyse the burden cognitive decline has on primary care.

Analysis will be conducted using variables from the Personality and Total Health (PATH) Through Life project. The use of primary care will be analysed by looking at Medicare records of GP visits that have been linked with PATH data. The aim for the final level is to analyse whether hospitalisation is predictive of, or is correlated, with cognitive decline. Hospitalisation data came from ACT Admitted Patients Data Collection and the ACT Emergency Department Data Collection, which has been linked to PATH data.

Back to top

Infections in childhood: risk factors, sequelae and health system burden: A NSW population-based data linkage study Professor Louisa Jorm, Centre for Big Data Research in Health, University of New South Wales

This study uses linked data to examine infections in childhood, their risk factors, sequelae and health system burden. The infections of interest include pertussis, influenza, invasive pneumococcal disease and meningococcal disease; sequelae of specific interest include seizure disorders and other neurological conditions, asthma, chronic lung disease and other respiratory conditions, otitis media, chronic gastrointestinal disease and chronic urinary tract infections. The use of linked data sets assists to examine the reporting of the conditions, to investigate the roles of maternal, child, geographic and health service factors in influencing susceptibility and short- and long-term outcomes. This study will also estimate the health system burden associated with childhood infections, including financial costs and bed days.

The study population includes all children with a birth record (live births only) in the NSW Perinatal Data Collection between January 1994 and December 2012. This cohort was linked by the CHeReL to other records in the NSW Perinatal Data Collection, NSW Notifiable Conditions Information Management System, NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, NSW Registry of Births Deaths and Marriages death registrations, ABS mortality data collection, ABS Perinatal Deaths data and NSW Register of Congenital Conditions.

Back to top

Trends, health service use and complications following hospitalisation for low back pain Associate Professor Manuela Ferreira, Sydney Medical School and The George Institute for Global Health

In 2010-2011 alone, approximately 500,000 hospitalisations involving surgical procedures were performed in Australians with musculoskeletal disorders, main diagnoses being low back pain and arthritis. However, this strategy is expensive, exposes patients to greater risks and conflicts with the best available evidence. The aim of this study is to better understand the outcomes and variations of hospitalisation and emergency department presentation for low back pain. Patients admitted to hospitals and emergency departments with low back pain were identified using specific codes from the NSW Admitted Patient Data Collection (APDC)and NSW Emergency Department Data Collection (EDDC). Linked records from the APDC, EDDC and NSW RBDM death registrations for this cohort were extracted from the Master Linkage Key by the CHeReL.

Using this linked data researchers are able to look at measures of health care use including length of stay, cost of care, readmission to hospital, use of specialized services such as inpatient rehabilitation and referral to outpatient rehabilitation and admission to nursing homes. Other outcomes like mortality, re-operations, procedural complications and use of health insurance can also be examined.

Back to top

Observational Australian Study investigating the epidemiology, outcomes and management of non-traumatic subarachnoid haemorrhage (OASIS study) Associate Professor John Worthington, Liverpool Health Service, University of New South Wales

Patients are often assessed and then discharged from a hospital Emergency Department (ED) without being admitted to a hospital ward. While the majority of these decisions are appropriate, some patients re-present within a short period

of time and require hospital treatment. In some cases, these re-presentations indicate the patient was initially misdiagnosed and the opportunity to provide timely treatment to produce more favourable health outcomes may have been missed.

Non-traumatic subarachnoid haemorrhage accounts for 5% of all strokes yet is associated with the greatest number of quality-of-life-years-lost of all stroke sub-types (fatality is 30-50% within 30-days). Urgent, definitive treatment of causative arterial aneurysms greatly reduces the risk of catastrophic re-bleeding in the days after a first subarachnoid bleed. While many patients with subarachnoid haemorrhage are critically ill at the time of presentation, a sizeable proportion are ambulant and conscious and present with symptoms shared with less serious conditions that can be safely managed in a community setting; such cases may be challenging to correctly diagnose.

Using data-linkage, this study examines the risk of hospital admission or death due to subarachnoid haemorrhage up to 30-days after discharge from ED, and aims to benchmark the rate of misdiagnosis to other acute conditions which also have serious consequences and risk being misdiagnosed because symptoms are shared with less serious illnesses. Data from the NSW Emergency Department Data Collection (presentations) and NSW Admitted Patient Data Collection (hospital admissions) from 1 January 2005 onwards were linked by the CHeReL to subsequent hospital admissions, ED presentations, and NSW Registry of Births Deaths death registrations and ABS mortality data to determine outcomes such as case-fatality, fatality up to one-year and beyond, hospital re-admission and time spent in hospital after a subarachnoid haemorrhage.

The results of this study are expected to highlight potential deficiencies in current patient care, with a particular emphasis on subarachnoid haemorrhage, the most fatal and devastating form of stroke. By identifying predictors of misdiagnosed subarachnoid haemorrhage, the study will inform clinical education and identify system, patient and disease factors that may be translated into clinical and system redesign to remedy gaps in current care, improving patient safety and avoid delays in definitive diagnosis and treatment. The study is currently underway.

Back to top

Advanced heart failure management and mechanical circulatory assist therapy - a retrospective activity based costing study Associate Professor Christopher Hayward, Heart Lung Clinic, St Vincent’s Hospital, Darlinghurst

Heart failure (HF) has a prevalence of 1–2% in the western world. Advanced HF (AHF) affects 10% of the HF population and is associated with an extremely poor quality of life, recurrent hospitalizations, and a mortality of up to 50% at 1 year

. It is one of Australia's most prevalent, disabling, chronic and costly conditions. 300,000 Australians suffer some degree of heart failure, and conservatively 3000 deaths each year can be attributed to it.

As the condition worsens, available treatments escalate in cost, to include intravenous medications, supportive device therapies, and heart transplantation. Commonly used devices scale up, as the patient's acuity and prognosis worsens, to include implantable defibrillators, biventricular pacing and implantable ventricular assist devices (VADs).

Study researchers assessed the cost of advanced heart failure management in patients waitlisted for heart transplantation and receiving treatment at St Vincent's Hospital Sydney , between 2009 and 2012, was linked by the CHeReL to the NSW Emergency Department Data Collection, NSW Admitted Patient Data Collection, NSW Registry of Births, Deaths & Marriages death registrations and ABS Mortality data collection.

An understanding or the economic costs of managing advanced heart failure will benefit the wider community through assisting the process of informed governmental decision making with regards health care funding.

Back to top

EXTending the ANZDATA Registry by linking to administrative datasets (EXTANZ) Associate Professor Martin Gallagher, Renal Policy Program, The George Institute for Global Health

The burden of end stage kidney disease (ESKD) is falling upon increasing numbers of patients and families in Australia and despite much of the increasing financial cost being borne by the wider Australian community, outcomes for these patients remain poor. The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) has made invaluable contributions to knowledge of the patient journey after commencement of renal replacement therapy. The registry, however, is limited in its information around health service utilisation, such as accessing health care providers, hospitalisations, procedures and medications. The EXTANZ project therefore aimed to expand the ANZDATA Registry dataset to include additional information on outpatient medical consultations, outpatient medicine usage and hospitalisation events.

Cohort data for incident maintenance renal replacement therapy patients that commenced treatment at Concord Repatriation General Hospital, Royal Prince Alfred Hospital, Royal North Shore Hospital or Sir Charles Gardiner Hospital between 2011- 2012 were linked by the CHeReL to the NSW Admitted Patient Data Collection and NSW Registry of Births, Deaths & Marriages death registrations for NSW patients. Patients who were resident within WA were also linked to the WA hospital morbidity data collection and WA Mortality Dataset by

the WA Data Linkage Service, and to the Medicare Benefits Schedule and Pharmaceutical Benefits Scheme by the Department of Human Services.

Study researchers evaluated outcomes of mortality, health service utilisation, types of renal replacement therapy, medication types and specialist outpatient services, with the findings used to understand the impact of these additional healthcare activities upon the outcomes of patients receiving dialysis and transplantation.

The resulting dataset of this project provided researchers with additional information on the provision of health services and medications to kidney disease patients. Such information is likely to be shaping the poor patient outcomes, and once known, will be useful to inform government policy and improve public practice in coping with the disease.

Back to top

Detecting missed opportunities for earlier HIV diagnoses in NSW Dr Jeffrey Post, University of NSW and Prince of Wales Hospital

Survival is improved in people with HIV if they commence antiretroviral therapy before the CD4 T-cell count falls below 350 cells/uL; however up to 40% of people in NSW are diagnosed late, with a CD4-T cell count below 350. Late diagnosis is more common in people with heterosexual sex or injective drug use as a risk factor for HIV infection than in men who have sex with men. The National HIVTesting Policy now includes clinical indications for recommending an HIV test, and the NSW HIVStrategy identifies the reduction in late diagnosis as a priority area for action.

This study sought to identify opportunities for health care contact where an HIV test may lead to earlier diagnosis, plus investigate the duration between diagnosis of conditions which may indicate HIV, and identify access points for HIV testing to facilitate earlier diagnosis.

Record linkage provides an opportunity to investigate relevant events such as diagnoses, procedures or health care presentations prior to HIV diagnosis to investigate the study aims. Using the National HIV Register, all subjects diagnosed with HIV in NSW in the study period were selected as the cohort. The CHeReL linked these records to the NSW Central Cancer Registry, the NSW Notifiable Conditions Information Management System, the Admitted Patient Data Collection, and the Emergency Department Data Collection.

The ability to diagnose people with HIV earlier in the course of infection will facilitate earlier treatment and better outcomes for individuals. It will ultimately also reduce the cost of care and potentially contribute to minimising onward HIV transmission.

Back to top

Long term outcomes of an investigation for post-traumatic stress disorder (PTSD) among illicit drug users Dr Katherine Mills, National Drug and Alcohol Research Centre, University of New South Wales

The high prevalence of Post-Traumatic Stress Disorder (PTSD) among people who are dependent on illicit drugs has been clearly recognised in both the Australian and international literature. Despite this, research on treatment responses to this significant problem is sparse. Individuals with this comorbidity present a significant challenge to substance abuse treatment providers as they present with a poorer clinical profile, and have poorer substance abuse treatment outcomes, including higher hospital readmission rates. Consequently, they are a costly burden to the health care system.

A recently completed randomised controlled trial (RCT) of an integrated exposure-based treatment for PTSD showed that participants randomised to receive the treatment demonstrated a greater reduction in PTSD symptom severity compared to those randomised to receive usual care. Secondary analysis indicated that reductions in PTSD were associated with significant reductions in substance use.

This study seeks to extend these findings by examining the longer term impact of this treatment on health service utilisation and mortality - two important measures of outcome. To facilitate this, the CHeReL linked the RCT participant data to the NSW Admitted Patient Data Collection, the NSW Emergency Department Data Collection, the NSW RBDM death registrations, and the ABS death data. Findings from the study will contribute valuable information to knowledge of how best to treat people suffering from co-occurring PTSD and illicit drug use, which in turn could reduce health service use and mortality rates amongst PTSD sufferers.

Back to top

Family Mental Health and Pregnancy Outcomes: a program of population research Dr Fenglian Xu, The University of New South Wales

Mother's mental health is known to affect pregnancy outcomes. Research also shows that selected obstetric and perinatal events increase the risk of mother's admission to hospital with mental illness in the six months following a birth. This project will investigate the relationships between mental health and pregnancy outcomes using linked data from NSW Admitted Patient Data Collection, NSW Emergency Data Collection, NSW Perinatal Data Collection, NSW Registry of Births, Deaths and Marriages, Pharmaceutical Drugs of Addiction System and NSW Register of Congenital Conditions. The results of the study will be used to identify areas where a review of services and policies relevant to pregnant women with mental health and substance use problems would be most cost

effective. It will also inform policy and planning of mental health in the prenatal, pregnancy and postnatal care of all women.

Back to top

Chronic Disease Management Program (CDMP)(formerly 'State-wide Evaluation of the NSW Health Connecting Care Program') Dr Anne-Marie Feyer, The George Institute for Global Health

The NSW Health Connecting Care Program aims to deliver more effective care and support to people over the age of 16 years who are at high risk of being admitted to hospital due to their chronic conditions which are frequently exacerbated by social and economic circumstances. Using routinely collected health service data at NSW Health (NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, NSW Registry of Births, Deaths and Marriages), health service use will be examined among patients enrolled in the Connecting Care Program and compared to those not in the Connecting Care Program. Findings of this study will contribute to decisions about the future of the Connecting Care Program and public funding decisions around chronic disease management in general.

Back to top

Mothers and gestation in custody (MAGIC): Data linkage study of birth and neonatal outcomes of women in prison during pregnancy Prof Elizabeth Sullivan, University of Technology Sydney and The University of New South Wales

This study aims to assess the effect of incarceration during pregnancy on mothers and their newborn babies. A literature review of studies of pregnancy outcomes in prisoners, mostly from the USA where there is no universal health care, concluded that imprisoned women were less likely to experience poor perinatal outcomes than other disadvantaged women. However in Australia, women's pregnancies may be more adversely affected by incarceration as disparities between health care in and outside prison may not be as great.

Data linkage was used to investigate this question by comparing imprisonment pregnancy outcomes with four other groups:

- pregnancies in the same women when not in prison;
- pregnancies in other women who have spent time in prison when not pregnant
- pregnancies in ‘high risk’ women who have not spent time in prison (women with a history either of mental illness or substance use during or prior to the pregnancy);

- a randomly selected 10% sample of non–prisoner pregnancies.

This study used linked records from the NSW Perinatal Data Collection, NSW Register of Congenital Conditions, NSW Admitted Patient Data Collection, Pharmaceutical Drugs of Addiction System and Offender Information Management System.

Back to top

Estimating the prevalence and incidence of cardiovascular disease, chronic kidney disease and diabetes in NSW and WA, using linked hospital and deaths data Ms Anne Broadbent, Australian Institute of Health and Welfare

The National Centres for Monitoring Cardiovascular Disease, Diabetes and Chronic Kidney Disease, located at the AIHW and funded through DoHA, are responsible for monitoring patterns and trends in cardiovascular disease, diabetes and chronic kidney disease in Australia and for providing high quality, policy-relevant analysis on all aspects of the three diseases. This project will use linked hospital and deaths data obtained from NSW/ACT (NSW Admitted Patient Data Collection, Australian Bureau of Statistics, ACT Admitted Patient Collection) and WA. This project will provide insight into the accuracy of current estimates of the prevalence of CVD, diabetes and CKD and incidence of acute coronary syndrome and end-stage kidney disease.

Back to top

Reducing road traffic crashes through data linkage Dr Rebecca Mitchell, University of NSW

Good quality data on road traffic injuries and factors leading to vehicle crashes is essential to inform policy designed to reduce the burden of road trauma. However it is well recognised that comprehensive information on road traffic casualties can rarely be obtained from a single data source. This study aimed to address this through linkage of the Transport for NSW's Road Crash Analysis System and CrashLink data collections to the NSW Emergency Department Data Collection, the NSW Admitted Patients Data Collection, NSW Registry of Births, Deaths and Marriages deaths data and the Australian Bureau of Statistics Mortality data file over a 9 year period. Analysis of this linked data resource will provide a rich source of information not only about the circumstances associated with a road crash, but also about the nature and severity of the injuries sustained, treatment received and outcome for the patient. This information will guide approaches to injury risk management and road safety in NSW, including policy development by relevant government departments.

Back to top

Changing patterns in end of life care Mr Christopher McGowan, Silver Chain Group

Health care costs, and particularly, hospital costs are escalating across Australia at a rate disproportionately higher than that explained by the ageing of the population.

The aim of this project is to identify whether patterns in end of life care are changing; that is, is the proportion of costs used in the last years of life increasing as a percentage of whole health care consumption? To do this, the investigators will use linked hospital utilisation and mortality data from various states to better understand changes in end of life care.

It is hoped that this research will assist policy makers and planners to adequately plan for the future.

Back to top

Regional level modelling of patient catchment areas - defining and analysing variation in primary health care need, utilisation and cost Dr Federico Girosi, University of Western Sydney

The study aims to investigate geographic variation of health status, healthcare need, utilisation and cost in New South Wales in order to provide a more effective means of resource allocation for improving health equity and health outcomes. The first step toward this goal is the definition of appropriate geographic areas that constitute the basis for the spatial analysis. The investigators will create geographical areas which reflect primary healthcare utilisation called "catchment areas". The complex relation between healthcare need, utilisation and cost will be disentangled using 45 and Up Study data, linked to routinely collected health services and outcomes data (hospital admissions, cancer registrations, and cause of death). The investigators will model policy interventions that alter important determinants of outcomes such as funds distribution or access to care in order to understand how better allocation of resources can lead to improved health for all.

Back to top

A population-based examination of cancer in NSW farmers Associate Professor Tony Lower, University of Sydney

Australian farmers have significantly elevated rates of death from prostate and lympho-haematopoietic cancers compared to other Australians. This project is a population-based examination of risk factors, incidence, screening, diagnosis, treatment and outcomes of major cancers in NSW farmers. The study will draw

on data identifying those respondents that have indicated that they live on a farm, within the 45 and Up Study. This study has four components:

- A comparison of farm and non-farm respondents in relation to screening behaviours and other matters relating to cancer occurrence and control;
- Linkage to the NSW Pap Test Register to obtain a more complete picture of screening behaviour of farm residents;
- Linkage to the NSW Central Cancer Registry and NSW Admitted Patients Data Collection to ascertain issues related to diagnosis and primary management of all cancers; and
- Linkage to the MBS, PBS, NSW Central Cancer Registry, NSW Registry of Births, Deaths and Marriages and the NSW Admitted Patients Data Collection to investigate treatment and survival in the farm and non-farm cohorts of non-Hodgkins lymphoma and prostate cancer.

Back to top

Emerging issues in maternal health Associate Professor Christine Roberts, The Kolling Institute, University of Sydney

Improved care for chronic diseases and delayed childbearing mean that there are increasing numbers of pregnant women with chronic medical conditions. Information on pregnancy and subsequent maternal and child health outcomes associated with these pregnancies is lacking. Many conditions and procedures are rare in pregnant women making them difficult to study, with research limited to case reports or case series. Thus specific management guidelines often do not exist and long term consequences of pregnancy outcomes remain unknown.

This project consists of 11 studies to examine emerging issues in maternal health and investigate pregnancy, maternal and child health outcomes for women who have the following conditions: prosthetic heart valves; organ transplant; intra-hepatic cholestasis of pregnancy; inflammatory bowel diseases; bleeding and blood disorders; breast surgery prior to pregnancy; early onset cardiovascular disease; incisional hernia repair; gynaecological procedures; autoimmune diseases and sleep disorders. For each condition the aims are to assess the burden of disease in the NSW population; examine fertility rates; describe when and how women are delivered; and compare the risk of adverse pregnancy outcomes, maternal health and infant and child outcomes compared to women without the condition.

The study used the Australian birth cohort, established with linkage undertaken by the CHeReL. Data sets used in this study were the Pacific Laboratory Medicine Service (PaLMs); the NSW Perinatal Data Collection; the Register of Congenital Conditions; the NSW Admitted Patient Data Collection; the NSW Emergency Department Data Collection; the NSW Newborn Screening Programme; the NSW Pharmaceutical drugs of addiction system; the NSW Register of Births Deaths and Marriages birth and death registrations; the ABS Perinatal Deaths Collection; the NSW Perinatal Death Reviews; the Australian

Early Development Index; and NAPLAN data from the NSW Department of Education and Training.

For this study data linkage provides greatly enhanced potential for increasing the understanding of chronic diseases in pregnancy. Findings will feed into the development of clinical management guidelines which will ultimately improve maternal and child outcomes.

2012

Back to top

Participant eligibility confirmation and descriptive statistics for the NSW CLEAR study dataset Associate Professor Freddy Sitas, Cancer Council NSW

The NSW Cancer, Lifestyle and the Evaluation of Risk (CLEAR) study, is a case-control study conducted by Cancer Council NSW. The overall objective of the study is to assess the relationship between various lifestyle and genetic factors and risk of cancer in the NSW population. The study recruits patients 18 years or older diagnosed with any primary cancer within the last 18 months (cases) and their eligible cancer-free partners (controls). Participants are asked to fill an extensive lifestyle questionnaire and optionally provide a blood sample. Bloods are separated into plasma, serum and buffy coat and stored in the Cancer Council NSW Biobank. Further details about the CLEAR study are available here: **http://clearstudy.org.au**

Annual linkage of the CLEAR participant data to the NSW Cancer Registry, ABS mortality data and RBDM death registrations will allow the researchers to confirm and update information regarding cancer diagnosis and vital status for the study participants, resulting in a complete and verified dataset

Back to top

NSW Cancer Registry reporting project utilising linked administrative data to examine care, treatment patterns and health outcomes for people with cancer Ms Deborah Baker, Cancer Institute NSW

The objective of this linkage is to develop a deidentified data set with the NSW Central Cancer Registry and the Clinical Cancer Registries, the Admitted Patient Data Collection, Emergency Department Data Collection, NSW Registry of Births deaths and Marriages death data, and the Australian Bureau of Statistics mortality data. The linked data will enable significant improvement in cross sectional and longitudinal evaluation and

monitoring of treatment and outcomes in people with cancer as recorded across these data sets. Study design for reporting activities will include patterns of care studies, cross sectional descriptive and historical cohort study designs using linked records.

Back to top

The utilisation of medications during pregnancy and the associated health outcomes Dr Alys Havard, The University of Western Sydney

This study aims to measure the extent to which medications are used prior to and during pregnancy and the associated health outcomes for both the mother and child. We will also examine the extent to which utilisation has changed in response to policy reforms, and whether differences in utilisation exist between sub-populations.

This is a large population-based cohort study, comprising all women who gave birth in NSW in the period 2003-2010, later updated to include births in 2011-2014. It uses Pharmaceutical Benefits Scheme data linked to state-based perinatal, hospitalisation, emergency department, death and birth defect records. The Australian Institute of Health and Welfare will perform the linkage of PBS records, while other records relating to NSW-based participants will be linked by the Centre for Health Record Linkage.

Our findings regarding the safety of medications will be important for informing guidelines regarding the prescription of these agents during pregnancy. Our findings regarding the utilisation of medications prior to and during pregnancy, as well as our evaluation of policy reforms occurring over the last decade, will guide policy decisions regarding the extent to which medication use prior to and during pregnancy should be encouraged or discouraged, and how this might be achieved, particularly for Indigenous and other disadvantaged mothers.

Back to top

Investigating the elements of care and health care costs associated with implementing chemotherapy protocols in NSW hospitals: Linkage to NSW data sets Dr Sallie-Anne Pearson, University of Sydney

The Pharmaceutical Benefits Scheme (PBS) is a federal program providing public subsidies for medicines based on their efficacy and cost effectiveness. The economic evidence used to determine PBS-listing is not accessible to health professionals and other decision makers however, despite their vital role in the efficient and equitable distribution of medicines, whether or not these are PBS-listed. The aim of this study is to address this through building a publically available economic evidence base to assist decision-makers

at hospitals and area health services make evidence-based decisions about funding cancer medicines.

Participants in this study are patients undergoing chemotherapy for breast, colorectal or lung cancer who consent to linkage of their data from the NSW Cancer Registry, Admitted Patient Data Collection, Registry of Births, Deaths and Marriages, Emergency Department data collection, Medicare and medical records. This linkage will enable the researchers to identify the individual care elements involved in administering specific chemotherapy treatment protocols, and estimate the costs associated with each care element. The models developed will be publicly available and have the flexibility to establish cost-effectiveness of deploying cancer treatments in specific locations.

Back to top

Effectiveness of an early intervention trial to prevent childhood obesity. Phase 2: Follow-up and cost effectiveness analysis Dr Alison Hayes, University of Sydney

The Healthy Beginnings trial aims to tackle the onset of childhood obesity by means of home visits by early childhood health nurses to first time mothers living in disadvantaged areas of Sydney. The intervention phase, which has already taken place, is during the infants' first two years of life. Phase 2 of the trial involves follow-up to age 5 years including a cost-effectiveness analysis of the intervention compared to normal care using linked NSW (Admitted Patient Data Collection and Emergency Department Data Collection) and Commonwealth (MBS and PBS) health records. Economic evaluation will be carried out from the perspective of the health care provider. The objectives are to establish cost-effectiveness using a number of outcomes at different ages. Additionally, a cost-utility analysis will examine incremental cost per QALY at 5 years. The study will establish effectiveness, cost-effectiveness, sustainability, acceptability and the costs of rolling out the intervention to a wider population.

Back to top

Coming of Age Study: does the type of hypertension in pregnancy determine future cardiovascular risk? Prof Annemarie Hennessy, University of Western Sydney

Preeclampsia remains a leading cause of maternal morbidity and mortality and in Australia it affects up to 10% of all deliveries. Preeclampsia can be defined as a multi system disorder that is characterised by hypertension and affecting one or more other organs. The underlying cause of preeclampsia is still not fully understood but what is known is that it causes endothelial damage which may increase the risk of these women developing cardiovascular disease in later life.

Records for women giving birth at the Royal Prince Alfred Hospital during the period 1980-1989were linked to the Admitted Patient Data Collection and mortality data. Analysis of this linked dataset will allow the researchers to determine if women who have experienced high blood pressure complications in their pregnancy are at greater risk of developing long term health problems, such as ongoing hypertension, heart disease or cardiovascular disease, and have a higher mortality rate than women who remained normotensive during pregnancy.

Back to top

Pharmacotherapy for smoking cessation during pregnancy and the inter-pregnancy period Dr Alys Havard, Centre for Big Data Research in Health, UNSW

Maternal smoking during pregnancy is a leading cause of adverse outcomes, with increased risk of placental abruption, preterm delivery, low birth weight and perinatal mortality. The harms of maternal smoking extend into childhood with increased risk of sudden infant death syndrome, asthma, lower respiratory illnesses and hospitalisations. The risk of adverse outcomes can be reduced by quitting; however only 4-29% of women smoking in early pregnancy stop, and heavy smokers have the lowest cessation rates. Although there has been some uptake of smoking cessation pharmacotherapies among pregnant smokers, it is unclear whether this is advisable, as the benefits and risks of using these medications during pregnancy have not been adequately assessed.

This project uses a retrospective cohort methodology to measure utilisation of pharmacotherapies for smoking cessation during pregnancy and inter-pregnancy periods and in different sub populations; the extent to which the use of pharmacotherapies during pregnancy has changed with the introduction of policies subsidising their use; investigate rates of smoking cessation associated with the use of smoking cessation pharmacotherapies during pregnancy; and investigate maternal and child outcomes associated with use of smoking cessation pharmacotherapies during pregnancy.

For this study the CHeReL linked records from the NSW Perinatal Data Collection, the NSW Admitted Patient Data Collection, the NSW Emergency Department Data Collection, the NSW Register of Congenital Conditions, the NSW RBDM births and death registrations, and the ABS Mortality Data. Personally identifiable variables from NSW collections were provided to the Australian Institute of Health and Welfare for linkage to the Pharmaceutical Benefits Scheme data. Records from Western Australia were also included in the study. Findings from this project will provide valuable evidence to inform guidelines for smoking cessation during pregnancy and the level of risk associated with their use.

Back to top

The use of medications for diabetes during pregnancy and the associated health outcomes Dr Alys Havard, Centre for Big Data Research in Health, University of NSW

Gestational diabetes (GDM) and pre-existing Type II diabetes complicates up to 10% of Australian pregnancies, and the incidence is increasing. There is clear evidence that uncontrolled diabetes is associated with adverse maternal and foetal outcomes, the risk of which is reduced when blood glucose is controlled. Insulin is the standard pharmacotherapy for diabetes in pregnancy, but it is expensive and therefore heavily subsidised; plus involves daily injections and may cause weight gain and hypoglycaemia. Despite clinical trial evidence showing that oral hypoglycaemic agents (OHA's) are safe, they continue to be listed as Category C in pregnancy, implying they are harmful to the foetus.

Large scale population based linkage studies have the potential to investigate these issues. Using a large cohort of mothers the study aims to investigate short- and long-term complications due to pre-existing type II diabetes and GDM among Australian mothers; and explore the utilisation and effectiveness of OHAs and insulin during pregnancy and associated health outcomes for mothers and babies. Variations in diabetes medication utilisation during pregnancy will also be investigated by population sub groups. For this study the CHeReL linked records from the NSW Perinatal Data Collection, the NSW Admitted Patient Data Collection, the NSW Emergency Department Data Collection, the NSW Register of Congenital Conditions, the NSW RBDM births and death registrations, and the ABS Mortality Data. The CHeReL also provided the Australian Institute of Health and Welfare with personally identifiable variables from NSW data collections for linkage to the Pharmaceutical Benefits Scheme.

Findings from this study will provide valuable evidence to inform clinical practice guidelines for diabetes management in pregnancy. If the use of OHA's is demonstrated to be safe during pregnancy, a change in clinical practice may also result in improved outcomes for mother and baby and result in substantial health system cost savings.

Back to top

Patient waiting times at public hospitals and the demand for private care Prof Elizabeth Savage, University of Technology Sydney

Reducing public hospital waiting times is a central issue in the Australian health care debate. Subsidies to private health insurance and increased expenditures to shorten waiting times both aim to ease pressure on the public hospital system. However there is no empirical evidence to evaluate alternative and possibly more effective sradhapolicies. This study aims to address this through the linkage of records from the NSW Admitted Patient Data Collection, Waiting

Times Data Collection, Emergency Department Data Collection, mortality registrations and the 45 and Up Study. Specifically the study aims to develop:

- a descriptive econometric analysis of waiting times;
- a model to describe the demand for private health insurance and public-private hospital choice; and
- an analysis of the impacts of waiting times on subsequent health outcomes and health care expenditure.

This research will be the first internationally to develop a model of insurance purchase and hospital choice which incorporates expectations about waiting times. It will allow the researchers to predict the outcomes of policies directed at private health insurance or at expanded public hospital capacity.

Back to top

Developmental Trajectories in Australia: Perinatal outcomes and child development (risk and protective factors) Associate Professor Sally Brinkman, Telethon Kids Institute

Governments are becoming increasingly interested in the early determinants of children's health, development and wellbeing in order to inform services needed to better support children and their families. Health and education research suggests that to do this, a comprehensive understanding of health, development and learning outcomes is required which necessitates information about child, teacher, school, community and societal factors.

In order to inform and improve services, and develop and implement universal and targeted strategies for improvement, an understanding of the complexities of the patterns of child development across population groups is needed. Such initiatives can be better informed through longitudinal population based data linkage systems.

This project aims to explore the relationship between perinatal outcomes (e.g. birth weight), developmental outcomes as measured by the Australian Early Development Index (AEDI), and resultant educational outcomes. By obtaining data from all States and Territories, it seeks to investigate both within and between jurisdictional differences in child developmental trajectories.

This project is the first of its kind in Australia to link person based perinatal and local education data with data from the National Australian Early Development Census (AEDC) across jurisdictions. On behalf of NSW and the ACT, the CHeReL linked the NSW and ACT Perinatal Data Collections, NSW and ACT Births data, NSW Best Start Kindergarten Assessment, NSW School Enrolment Form data, NSW and ACT National Assessment Program Literacy and Numeracy (NAPLAN) data, ACT Performance Indicators in Primary Schools (PIPS), ACT Kindergarten Health Check data, ACT School

Enrolments, and ACT School Attendance data, to the AEDC held by the Australian Government Department of Education.

This project provides the opportunity to measure the impact of perinatal outcomes on educational attainment and health outcomes, and to explore these differences by population subgroups and characteristics. The results will be used to inform services and provide essential support for children and families.

Back to top

The Australian Perinatal mental health reforms: using population data to evaluate their impact on service utilisation and related cost-effectiveness Prof Marie-Paule Austin, University of New South Wales

Mental health problems associated with the perinatal period are recognised as a major public health issue with significant morbidity and costs. The last decade has seen a burgeoning of perinatal mental health initiatives in Australia, including the National Perinatal Depression Initiative (NPDI), yet there is currently a gap in the understanding of how well these initiatives have met their goal of improving maternal and infant mental health outcomes.

This project will examine the impact of reforms on maternal and infant health outcomes, service utilisation and the likely cost-effectiveness of these reforms through linkage of NSW health records (Perinatal Data Collection, Admitted Patient Data Collection, Registry of Births, Deaths and Marriages deaths registrations), in addition to generation of perinatal-specific Medicare Benefits Schedule summary data; economic and policy analyses; and key stakeholder consultations.

The findings from this project will provide information for the provision of effective mental health services to this vulnerable population. It will put Australia at the forefront of policy planning, analysis and cost-effectiveness evaluation in the field of perinatal mental health.

Back to top

Can NSW Admitted Patient Data improve the quality and coverage of the NSW Register of Congenital Conditions? Dr Lee Taylor, NSW Ministry of Health

The NSW Register of Congenital Conditions (RoCC) is a statutory data collection under the NSW Public Health Act 1991. Under the Act, doctors, hospitals and laboratories are required to report certain congenital conditions diagnosed during pregnancy, at birth, or up to one year of age to the RoCC. The RoCC is used to provide information to assist in responding to apparent clusters of congenital conditions occurring in the community, to identify changes in

incidence that may require investigation, and to monitor the occurrence of congenital conditions for service planning purposes.

A recent review found that a proportion of congenital conditions had not been reported to the RoCC. Linkage of the RoCC to the Admitted Patient Data (APD) collection, combined with medical record review, will enable the researchers to investigate the:

- number and type of congenital conditions reported to the APD and not to the RoCC for 2009
- sensitivity and specificity of congenital condition codes on the APD for registration on the RoCC
- quality of reporting of congenital condition codes on the APD by comparing with the RoCC for cases which are reported on both data collections.

Back to top

Health service use and outcomes following colorectal resection: a population-based health record-linkage study Prof Marc Gladman, University of Sydney

Surgical treatment for colorectal disease varies greatly depending on the disease and its severity. Main indications for colorectal resection include a range of conditions affecting the bowel and rectum. Little is known about the characteristics, trends and health service utilisation of patients undergoing colorectal resection; and impact on their health outcomes. This study aims to assess mortality, morbidity and health outcomes of patients undergoing colorectal resection in New South Wales. The project will involve analysis of record-linked data from the Admitted Patient Data Collection, NSW Central Cancer Registry, NSW Emergency Department Data Collection, NSW Registry of Births, Deaths and Marriages (RBDM) and ABS Death Registrations. Findings will provide important information on factors associated with health outcomes following colorectal resection and health services use, and inform future patient counselling and initiatives for improving health service planning and provision of care.

Back to top

Development of a risk score predicting colorectal cancer among Australian men and women in later life Prof David Roder, University of South Australia

Colorectal cancer (CRC) is a leading incidence and mortality cancer. Incidence rates vary widely and are thought to be influenced by diet and other lifestyle factors. As a consequence, CRC is thought to be amenable to prevention. Prioritizing preventative initiatives and screening towards high-risk individuals may enhance the cost-effective use of scarce health service resources. There has been little research, however, on development of risk models for predicting a

person's absolute risk of CRC. The main aim of this project is to develop a simple practical and informative CRC risk model for predicting absolute risk of CRC in later life, using data from the 45 and Up Study linked to NSW death records, NSW Central Cancer Registry (CCR) records and NSW Admitted Patients Data Collection (APDC) records. Results will be of direct relevance for planning individual patient care and service delivery in Australia, while also making a contribution to world knowledge.

Back to top

Economic analysis of the social costs of skin cancer in NSW Ms Melanie Crane, Cancer Institute NSW

Few economic evaluations have been conducted in Australia to measure the magnitude of the impact of skin cancer. There are large gaps in understanding the wider costs of skin cancer, particularly the impact of non melanoma skin cancer. This project aims to quantify the direct and indirect costs to society associated with skin cancer in NSW and to analyse the cost effectiveness of the Cancer Institute NSW skin prevention activities in NSW, using linked health records from the NSW Central Cancer Registry, NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, 45 and Up Study, NSW Registry of Births, Deaths and Marriages and Australian Bureau of Statistics. With a clearer understanding of the cost of skin cancer, the level of investment required for prevention can be better defined.

Back to top

Medication use and health outcomes in the 45 and Up Study Prof Emily Banks, Australian National University

Medications are the mainstay of much clinical medicine, in terms of both individual and large-scale primary and secondary prevention of disease. However, it is widely acknowledged that use of medicines is far from optimal; significant illness, disability and loss of life could be prevented by appropriate use of medicines.

This project uses linked data (The 45 and Up Study, NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, NSW Central Cancer Registry, NSW RBDM death registrations and ABS mortality data) to investigate the relationship between medication use and personal characteristics, health services use, health outcomes and costs, and to examine how these relationships vary according to a range of socio-demographic, lifestyle and health-related characteristics.

Benefits for the wider community will be related to an improved understanding of a range of issues relating to access to, use of and costs of health services, and the health outcomes of service use.

Back to top

The cost effectiveness of managing individuals at high risk of melanoma in a High Risk Clinic, compared with standard care Ms Caroline Watts, University of Sydney

The aim of this study is to determine if it is cost effective from the perspective of the Australian health system to manage individuals considered at high risk of melanoma, in a specialised setting i.e. a high risk clinic, compared with standard care. A clinic for individuals at high risk of melanoma was established at Royal Prince Alfred Hospital (RPAH), Sydney in 2006 with the aim of managing individuals at high risk more efficiently. It is hypothesized that melanomas will be detected earlier and there will be less excisions with a closely managed surveillance program. This hypothesis will be evaluated using data from individuals attending the high risk clinic at RPAH and data from the Melanoma Patterns of Care Study, as well as linked data from the 45 and Up Study, the Medicare Benefits Schedule (MBS), the NSW Central Cancer Registry (CCR) and the NSW Admitted Patient Data Collection (APDC). This research will provide evidence to allow the evaluation of costs and benefits of the high risk clinic model and will have direct policy implications for the management of individuals at high risk of melanoma in Australia.

Back to top

Last days of life study: Patterns of health services use and experiences of adult New South Wales residents in the year prior to death Prof Jane Ingham, Cunningham Centre for Palliative Care, Sacred Heart Centre and Prof Dianne O'Connell, Cancer Council NSW

The aim of this study is to describe patterns of health services use and experiences of adult residents of NSW during the year prior to their death.

Adults who died in NSW during 2007 were identified from the Registry of Births Deaths and Marriages death registration and ABS mortality collections and their linked records from the NSW Central Cancer Registry, Admitted Patient and Emergency Department Data Collections were extracted. Analysis of these data will provide information that can form a foundation for addressing the future health services needs of people nearing the end of their life across all areas of NSW.

Back to top

Comprehensive linkage of maternal and infant health data for monitoring health outcomes and planning of

maternity services in NSW Dr Christine Roberts, NSW Department of Health; Kolling Institute of Medical Research, University of Sydney

This study aims to make a complete assessment of maternity care services in NSW for births up to one year following delivery. The study aims to investigate maternal and infant health outcomes for initial and subsequent pregnancies. Areas to be assessed include:

- effectiveness of health services in reducing preventable morbidity and mortality;
- impact of regionalised maternity care services on maternal and infant morbidity and mortality;
- role of within-labour factors on outcomes for low risk women;
- role of antenatal transfer in maternity care;
- recurrence of pregnancy conditions in a subsequent pregnancy, and associated risk factors; and
- patterns of readmission and morbidity associated with particular obstetric procedures, pregnancy conditions and outcomes.

The CHeReL linked the following NSW datasets to enable this program of research: the Midwives Data Collection, Registry of Births, Deaths and Marriages birth, death and perinatal death registration data, Australian Bureau of Statistics mortality data, Admitted Patient Data Collection, Birth Defects Register and the Perinatal Death Review Database.

Back to top

The evaluation of a state-wide innovative patient safety improvement system on reducing hospital mortality and other adverse events - a population-based mixed-method study Associate Professor Jack Chen, University of New South Wales

In Australia, over 16% of hospital admissions are found to be associated with adverse events, including 5% resulting in patient death. After a major health review in 2008, NSW Health implemented a patient safety improvement program called Between the Flags initiated by the Clinical Excellence Commission to improve the way hospital staff recognise and respond to patients when their clinical condition starts to deteriorate. This study aims to examine the effectiveness of Between the Flags across NSW hospitals, using linked data from the NSW Admitted Patient Data Collection and the NSW Registry of Births, Deaths and Marriages.

Back to top

Comparison of Outcomes and Health Service Utilisation in Rural Versus Urban Renal Failure Patients in New South Wales Dr Sradha Kotwal, The George Institute

This study identified patients with End Stage Kidney Disease (ESKD) and chronic kidney disease (CKD) in NSW from the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) and the Admitted Patient Data collection, respectively. Linked cancer notifications, hospitalisations and death records were then extracted for these patients to enable investigation of outcomes and health service utilisation in those from rural compared to urban centres.

Specifically, the study aimed to:

- Explore patterns of access to Renal Replacement Therapy (RRT) and its differential use in rural and urban patients
- Compare outcomes (mortality, late dialysis preparation, hospitalisation, length of stay) of rural versus urban CKD and ESKD patients in NSW
- Explore the impact of additional chronic disease diagnoses (e.g. cardiovascular disease, diabetes, and cancer) upon these outcomes in CKD and ESKD patients.

This research will define the geographical distribution of CKD and ESKD and the demand for RRT in the rural NSW population. It will also delineate differences in nephrology service provision between rural and urban settings along with the financial and policy implications. This will allow us to design and implement strategies to provide optimal health care in a rural setting in the future.

Back to top

Australian Longitudinal Study on Women's Health (Data Linkage Project) Dr Deirdre McLaughlin, University of Queensland

The Australian Longitudinal Study on Women's Health (ALSWH) has been collecting information on the health and wellbeing of Australian women since 1996. The overarching aim of the ALSWH is to provide a strong, valid evidence-base which can be used by Commonwealth and State Governments for prioritising health policy and planning. To further advance this aim, this study linked the ALSWH with several administrative datasets - NSW Admitted Patient Data Collection, NSW Central Cancer Registry and the NSW Perinatal Data Collection. The addition of these linked data will enhance the ability of the ALSWH to deliver sound, up to date information on women's health and will allow for validation of ALSWH data collected on significant health events against official records. These data, together with similar data obtained from other Australian States for ALSWH participants will allow the researchers to

conduct longitudinal, epidemiological analyses using both survey responses (self-reported) and objective measures of health.

Back to top

Use of primary care, health events, health services use and costs in the 45 and Up study Prof Louisa Jorm, University of Western Sydney

This study will link data from the 45 and Up study to a range of administrative datasets, namely admitted patient, emergency department, cancer registry, mortality, MBS and PBS data. Analysis of this linked dataset will provide important evidence regarding the relationship between use of primary care and subsequent health services use and health outcomes, as well as comprehensive data about health service costs. The contributions of person-, geographic- and service-level factors to these relationships will be examined. When complete, the project will provide data that are specific to the Australian context at the same time as contributing to knowledge internationally.

Back to top

Linkage of population health datasets to examine outcomes of health care and for population surveillance of diseases and conditions in NSW Dr David Muscatello, NSW Department of Health

Linked NSW administrative datasets have become a critical resource for the public health system to be able to carry out its core business. These linkages allow the public health system to better identify issues of population health importance, to plan services or interventions to address these problems, and provide an improved source of data allowing monitoring and evaluation of the effectiveness of services and interventions.

Specifically, the linked datasets allow studies including examination of clinical care pathways for stroke, diabetes, asthma and other chronic diseases, surveillance of infectious diseases, and patterns of re-presentation to ED, readmission to hospital and mortality associated with particular medical conditions and procedures.

Back to top

Using novel record-linkage to assess the association between maternal and newborn thyroid hormone levels and birth outcomes Dr Natasha Nassar, University of Sydney

Adequate maternal and fetal thyroid hormone (TSH) levels during pregnancy are important for correct maturation of the central nervous system of the fetus and subsequent neurodevelopment of the child. Maternal or infant thyroid disease has been related to long-term neurocognitive impairment in children, however the impact of subclinical and subtle thyroid dysfunction is less well-established. This study aims to assess the feasibility of linking laboratory databases to routinely-collected birth and hospital data for assessing the association between TSH levels and adverse perinatal outcomes.

Back to top

Aboriginal mortality in a New South Wales urban cohort Prof Richard Taylor, University of NSW

The Aboriginal Medical Service Co-op Ltd, Redfern, (AMS) has been providing medical care to Aboriginal clientele since its inception in 1971. Through linkage of AMS records to the Registry of Births, Deaths and Marriages and ABS mortality data, this study will investigate sex-, age- and cause-specific mortality rates in a primarily urban, entirely Aboriginal population spanning almost forty years. This will provide a longitudinal analysis for the first time of mortality and cause of death in a known Aboriginal population of substantial size in New South Wales.

2011

Back to top

Identifying predisposing factors for, and the consequences of, common and emerging infectious diseases: A prospective cohort study of adults Dr Bette Liu, Faculty of Medicine, University of New South Wales

This project aims to investigate the factors that predispose adults to common 'notifiable' infections, and the impact these infections have on health many years after the initial infection occurred. The study will follow participants recruited into the 45 and Up Study, and use data linkage to determine whether a history of exposure to different infectious agents affects risk of hospitalisations, death from different causes or risk of cancer. It will also investigate whether modifiable behavioural factors increase the risk of developing such infections. The results of the study should lead to a better understanding of the role of many important infectious diseases on the health of Australian adults.

Back to top

Interactions of Cancer & Chronic Kidney Disease Dr Germaine Wong, Centre for Kidney Research, The Children's Hospital Westmead

Previous work by this research team has shown that people with chronic kidney disease (CKD) experience a two and threefold increased risk of cancer at most sites compared with the general population, and that the increased risk begins in people with mild to moderate kidney disease. However, the relationship between progression of CKD over time and the effect of mild to moderately reduced kidney function on cancer specific mortality remains unclear. Record linkage between data from the Blue Mountains Eye Study (a population-based cohort study) and the NSW Central Cancer Registry will allow determination of whether reduced kidney function is an independent predictor for site-specific cancers and overall survival among people with CKD

Back to top

What are the clinical and biochemical determinants of health service use by participants in the Hunter Community Study? Prof John Attia, University of Newcastle

The Hunter Community Study is a population-based prospective cohort study established to assess factors important in the health, wellbeing, and social functioning of older Australians. The participants were drawn from the Hunter Region of NSW, aged 55 to 85 years and have provided health data in the form of clinic assessments, surveys and blood samples. The current study will link the records of over 2500 of the participants to the Admitted Patient Data Collection, the Emergency Department Data Collection, the Central Cancer Registry and mortality datasets. This linked dataset will allow the researchers to identify and test the clinical and biochemical predictors of acute public and private hospital service utilisation, and the reasons for these visits in a representative sample of ageing Australians.

Back to top

Place of birth and perinatal outcomes in New South Wales Associate Professor Elizabeth Sullivan, University of New South Wales

This project aims to examine perinatal outcomes of women who intend to give birth in different settings: birth centres, primary maternity units, at home and in hospital labour wards. The study will also evaluate whether place of birth has an influence on the diagnosis and outcome of congenital anomalies, and examine fetal growth parameters in relation to place of birth. Records from the NSW Perinatal Data Collection, Admitted Patient Data Collection, Register of Congenital Conditions, Perinatal Death Reviews, ABS mortality data and the

Registry of Births, Deaths and Marriages death registration data will be linked for the period 2001-2009.

Back to top

Development and evaluation of composite clinical indicators of hospital performance for comparative assessment of the quality of surgical care for colorectal cancer. Professor Jane Young, University of Sydney

There is evidence that clinical care for colorectal cancer is highly variable and not in accordance with evidence based clinical practice guidelines. Accurate and timely clinical audit using measures of clinical performance associated with patient outcomes is essential to monitor the quality of clinical care; however there is no established ongoing monitoring system for clinical audit of colorectal cancer in NSW. This study aimed to investigate the use of currently collected data to improve timeliness and reduce the resource intensiveness of ad hoc clinical audit against practice guidelines. Specifically the study aimed to describe hospital variation in processes and outcomes for patients with colorectal cancer, and identify patient, surgeon and hospital related factors contributing to the observed variation. The study will also attempt to develop a set of hospital level process and short term clinical outcome measures that are associated with longer term survival, plus investigate the strengths and limitations of currently collected data items available for clinical audit.

For this study the CHeReL linked the NSW Central Cancer Registry to the six NSW clinical cancer registries, the NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, NSW RBDM death registrations and ABS mortality records.

Findings from this study will inform the development of a set of indicators suitable for clinical audit, and the utility of existing data for this purpose. If successful this information will be a valuable factor in the development of an ongoing clinical audit for colorectal cancer, which will ultimately improve outcomes for people with this cancer.

Back to top

Development of Diabetes Following Gestational Diabetes: A Population Data Linkage Project Associate Professor Wah Cheung, Westmead Hospital

Gestational diabetes (GDM) is a transient form of diabetes which occurs in pregnancy, but is associated with a higher risk of diabetes later in life. This study aims to determine the relative likelihood of developing diabetes for women who

had GDM compared to those who had normal glucose tolerance in pregnancy, in an entire population. This will be achieved through linkage of data from the NSW Perinatal Data Collection and the National Diabetes Services Scheme

Hormone therapies for early breast cancer; health outcomes and policy implications.

Professor David Preen, University of Western Australia

Breast cancer is the most common cancer in Australian women, with up to one in nine women expected to be diagnosed by age 85 years. Breast cancer incidence has seen a substantial increase over the last three decades, but correspondingly survival has also improved significantly. Clinical trial evidence has demonstrated that use of hormone-blocking therapies for at least five years after removal of the initial tumour significantly reduces breast cancer recurrence and mortality. However there is little evidence on the real world use of these therapies in Australian practice, which therapies or combinations of therapies are used, how adherent women are to these therapies, or the outcomes of long term use at the population level.

Using a cohort of women with breast cancer identified from the 45 and Up Study, the CHeReL linked these records to the NSW Central Cancer Registry, the NSW Admitted Patient Data Collection, the NSW Registry of Births Death and Marriages, and ABS mortality data. Pharmaceutical Benefits Scheme and Medicare Benefits Schedule data, available from the 45 and Up Study, were also included in the linked dataset.

Findings from the study will provide valuable evidence on the real world use of hormone treatment for breast cancer at a population level. This will facilitate the evaluation of the degree to which hormone therapy adheres to the current NH&MRC guidelines and determine factors predictive of non-compliance with clinical guidelines. Findings will increase understanding of the early and long term treatment of breast cancer with hormone therapies in Australian clinical practice.

Back to top

Augmenting date and cause of death information in the AHS Clinical Cancer Registries using the NSW Central Cancer Registry Prof Geoff Delaney, Liverpool Hospital and University of NSW

The objective of this linkage is to augment date and cause of death information in the Area Health Service (AHS) Clinical Cancer Registries using information held by the NSW Central Cancer Registry. This will enable AHS Clinical Cancer Registries to achieve a range of operational and strategic objectives, including monitoring survival outcomes for patients included in each Registry by stage,

treatment, facility and clinician. This information will be used to will inform best practice, plan and manage cancer services and support health system change

Back to top

Epidemiology and outcomes in Ambulance treated patients in NSW: the Australian Prehospital Outcomes Study of Longitudinal Epidemiology (APOStLE) Associate Professor Paul Middleton, Ambulance Research Institute

Ambulance data in NSW is not currently linked with other Health Department data, and therefore the outcomes for patients treated by and/or transported by ambulance services are not possible to assess. This study aims to address this by linking the Ambulance Computer Aided Dispatch and the Patient Health Care Record data to the NSW Emergency Department Data Collection, the Admitted Patient Data Collection and mortality data from the Registry of Births, Deaths and Marriages and the Australian Bureau of Statistics.

The linked dataset will enable investigation into the characteristics of patients suffering sentinel conditions, and to develop performance metrics for the major problems paramedics encounter: trauma, cardiac arrest and falls. This project will illuminate the nature and extent of these issues to inform decisions regarding performance measurement and safety and quality improvement.

Back to top

Understanding the factors related to health care use associated with falling in older people in NSW. Dr Rebecca Mitchell, University of NSW

Falls are one of the leading causes of injury morbidity and mortality in older people in Australia, with one third aged 65 years and over experiencing a fall, and half of people aged 80 years and over experiencing one or more falls each year. Fall related injuries are predicted to be an increasingly major cause of hospitalised morbidity in older people. This project sought to investigate and describe the sub-acute and non-acute health service use of fallers and non-fallers following Emergency Department presentation and/or hospital admission. The project aimed to examine the pattern and use of rehabilitation and other related health services for fall related injuries, estimate future demands for rehabilitation and other health services, and identify resource implications for future sub-acute and non-acute treatment following a fall related injury as the ageing population increases.

The Australian National Sub-Acute and Non-Acute Patient (AN-SNAP) is a casemix classification that includes four subacute care types (rehabilitation, palliative care, geriatric evaluation and management (GEM) and psychogeriatric care) and one non-acute care type. AN-SNAP is used to classify and fund

subacute and non-acute services in a number of Australian jurisdictions and internationally. The CHeReL linked AN-SNAP to the NSW Emergency Department Data Collection and the NSW Admitted Patient Data Collection for this study. Findings from the study will be used to inform initiatives to prevent and treat injuries and inform service development for rehabilitation services.

Back to top

Commonly performed interventions in childbearing women and related short and long term complications: An eight year data linkage study Associate Professor Hannah Dahlen, University of Western Sydney

The aim of this project is to determine the rate of maternal and neonatal morbidity and the economic consequences of commonly performed interventions such as induction of labour, labour augmentation and caesarean section.

The cohort for this study is all women who gave birth in NSW during July 2000 and June 2008, with linked records for these mothers and their babies extracted from the midwives, admitted patient, mortality and congenital condition data collections. This dataset will be used to examine short term outcomes such as maternal death, type of delivery and reason for caesarean section, and long term outcomes including death and readmission to hospital. The results of this study will provide a better understanding of the short and long term effects of medical and surgical intervention in labouring women.

Back to top

An analysis of the long term costs of disability arising from the Vietnam War. Dr Philip Clarke, Applied Economics

The long term health and support costs of war related disability are substantial. This study aimed to explore the impact of overseas deployment on health and disability in Veterans from the Vietnam War.

The project has two main objectives; firstly to gain an understanding of the factors which influence the rate and progression of veterans on return from operations applying for war-related disability pensions; and secondly to estimate the lifetime health and pension costs of Vietnam veterans by level of disability.

The study used a cohort of Vietnam Veterans obtained from administrative data held by the Department of Veterans Affairs, and service information from the Nominal Roll for the Vietnam War. Personal identifiers from these data were sent to the CHeReL so that the two data sets could be linked. The linkage pins were then sent back to the researchers to link information from the two sources. A

cohort of veterans engaged in ‘peacetime’ service only was developed to provide a comparison group.

Study findings will provide estimates of the incremental costs associated with active service overseas ie costs over and above Veterans with only peacetime service. This will inform an understanding of the long term resource implications of current and future deployments.

Back to top

Cause of death in men with prostate cancer: a population-wide data linkage study Dr David Smith, Cancer Council NSW

Too little is known about prostate cancer including its causes, the merits of screening for it or the outcomes of treatment. Much uncertainty stems from a lack of evidence about how deadly the disease is. Each year approximately 3,000 Australian men die from prostate cancer and a further 100,000 are living with the disease. This project will answer important questions regarding prostate cancer outcomes. It will 1) evaluate the hypothesis that "Men die with prostate cancer rather than of prostate cancer", 2) Determine whether the risk of death from suicide or heart disease is raised in men after prostate cancer diagnosis, 3) investigate whether men treated with hormone therapy are at higher risk of death from heart disease and 4) Determine whether men who report having PSA tests have lower risks of death from prostate cancer, 5) explore associations between statin use and outcomes for prostate cancer.

Each of these questions will be answered using linked data from the NSW Central Cancer Registry, the NSW Department of Health Admitted Patient Data Collection, Medicare, Pharmaceutical benefits scheme, the Register of Births Deaths and Marriages and Australian Bureau of Statistics mortality data, the 45 and Up Study and the NSW Prostate Cancer Care and Outcomes Study.

Back to top

An evaluation of the effectiveness of a statewide program of free pertussis vaccination of household adult close contacts for protecting infants against pertussis (the "cocoon strategy") in NSW Prof Peter McIntyre, National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases

This study aims to evaluate the effectiveness of a state-wide program of free pertussis (whooping cough) vaccinations to parents, siblings and other household carers in providing protection against severe pertussis in infants too young to be immunised themselves. Using linked data from the Notifiable

Conditions Information Management System, Perinatal Data Collection and mortality records, this research is required to provide direct evidence of a protective benefit from cocooning and to provide an estimate of the size of the benefit.

The results of this research are of direct interest to the NSW Ministry of Health, as part of their evaluation of the 'cocoon strategy'. The results are also expected to inform national immunisation policy decisions on pertussis control by the Australian Government, which takes advice from the Australian Technical Advisory Group on Immunisation. If found to be effective, this vaccination strategy may be considered for adoption as a long-term measure for population pertussis control, with the possibility of public funding under the National Immunisation Program.

Back to top

The impact of introducing Medical Emergency Teams on the reduction of hospital mortality and other adverse events in NSW Associate Professor Jack Chen, University of NSW

The high incidence of preventable adverse events and deaths in hospitals has triggered initiatives to improve the quality of care of acutely ill patients. These initiatives include the introduction of medical emergency teams (MET), outreach services or rapid response teams (RRT). These aim to identify seriously ill patients earlier in order to activate a timely and appropriate response and consequently improve patient outcomes.

In this study, linkage of hospital admission and mortality data over a one year period (2008) will enable:

- Assessment of the effectiveness of the MET system by comparing the incidence of mortality and other adverse events in hospitals with and without a MET system;
- Reporting of trends and the epidemiology of key adverse events and patient safety indicators in all NSW hospitals; and
- Understanding of possible variations in results across all hospitals, which will assist in informing further improvement and policy interventions

Back to top

Mortality rates after major surgery in New South Wales Prof Ian Harris, Liverpool Hospital

It is important for clinicians and patients to be aware of surgical risks and the chance of adverse effects such as mortality, particularly when making the decision to undertake surgical treatment. Few studies have explored postoperative mortality rates in Australia. This study will be an original retrospective investigation exploring 30-day and 12-month post-operative

mortality for a group of selected high volume procedures. Data from the NSW Admitted Patient and Emergency Department collections, along with mortality data from the Registry of Births Deaths and Marriages and the Australian Bureau of Statistics will be linked, extracted and analysed to investigate the relationship between mortality and institution, age and other sociocultural factors, for each procedure.

Back to top

Common Conditions, Health Outcomes and Health Services Use in 45 and Up study participants. Prof Emily Banks, Australian National University

Australia is currently facing a rapidly ageing population. There is a need for evidence to inform policy to address the associated public health issues. In particular, questions relating to access to, use of and costs of health services and the health outcomes of service use, for people in mid to later life.

This program of work uses linked data (The 45 and Up Study, NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, NSW Central Cancer Registry, NSW RBDM death registrations and ABS mortality data) and aims to investigate common health issues among 45 and Up Study participants including obesity, diabetes mellitus, joint replacement, chronic pain, fracture and prostate health, in relation to preventative factors, health outcomes and health care.

Benefits for the wider community will be related to improve understanding of a range of issues relating to access to, use of and costs of health services, and the health outcomes of service use. The program of research will have a focus on policy uptake, as such, it is also anticipated that the wider community will benefit from the implementation of evidence based policy.

Back to top

Novel and established risk factors for cardiovascular and metabolic disease: 45 and up Study data linkage project. Prof Emily Banks, Australian National University

Cardiovascular disease remains the biggest killer of adult Australians and a leading cause of morbidity and mortality worldwide. There is a lack of large scale Australian data about cardiovascular disease and the 45 and Up Study provides a unique opportunity to expand what is known about risk factors, health outcomes and health services use in relation to cardiovascular disease. The aim of this project is to investigate the relationship between a range of novel and established demographic, lifestyle and health-related risk factors and cardiovascular disease outcomes by linking baseline questionnaire data from the 45 and Up Study to data from the NSW Admitted Patient Data

Collection, NSW Emergency Department Data Collection, NSW Central Cancer Registry, NSW Registry of Births, Deaths and Marriages and Australian Bureau of Statistics.

Back to top

Validation study of Aboriginal identification algorithms in the APDC and ABS Mortality Data using the 45 and Up Study. Prof Louisa Jorm, University of Western Sydney

Indigenous status is known to be under-reported in hospital and deaths data, creating difficulties for research which aims to describe and understand Indigenous health issues using administrative data.

The aim of this study is to develop an algorithm to improve Aboriginal identification in hospital and death data by linking them to the 45 and Up Study, a questionnaire with self-reported Aboriginal status. Comparing identification in the APDC and NSW mortality data with Aboriginal status in the 45 and Up Study will allow the researchers to develop and test a set of algorithms and investigate which performs best to increase identification without resulting in too many false positives.

Back to top

Risk management and funding structures: an econometric panel data analysis of health insurance in Australia. Associate Professor Elizabeth Savage, University of Technology

Australia has complex and fragmented funding of its universal health insurance system. Health expenditures are split between patient co-payments and Commonwealth or State Government subsidies. Government subsidies via the public insurance system comprised 69% of total recurrent expenditure, with patients' co-payments comprising about 19% and private health insurance about 8% of the total. Individuals differ in their health status and access to health care – yet current funding arrangements take very limited account of individuals' risk of high health expenditures. A series of government reports have proposed taking greater account of expenditure risk in the allocation of health subsidies.

By estimating models of individual risk and investigating deviations between current health care subsidies and predicted risk, this study will produce the empirical results necessary to guide health funding. Specifically the project aims to provide a detailed analysis of the equity and efficiency of current subsidies; estimate models of total individual health expenditure risk; estimate a system of separate risk equations for medical, pharmaceutical and hospital exposures, and simulate the impacts on resource allocation of alternative subsidies.

For this study, the CHeReL linked records from the 45 and Up Study, which includes records from the Medicare Benefits Schedule and Pharmaceutical Benefits Scheme, to the NSW Admitted Patient Data Collection. The significance of this project lies in its contribution to new knowledge focused on the equity and efficiency of existing subsidies and the use of data to model health expenditure risk. It will address misallocation problems in the funding system, allow the integration of the existing fragmented system of financing health care and enable the design of a system of subsidies aligned with need.

Back to top

An individual-level study of suicide method substitution over time. Dr Matt Spittal, University of Melbourne

This multi-state study investigated patterns in the methods used in suicidal acts with the aim of understanding the potential for restriction of access to the means of suicide. In particular the study sought to investigate the extent to which individuals switched methods of suicide acts over time, and the characteristics predicting choice of method on each occasion. There is some evidence that restriction of access to firearms, pesticides, and domestic gas, and regulation of access to barbiturates and other drugs does reduce rates of suicide without method substitution; however to understand this fully the dynamics behind method substitution need to be better understood.

For this study the cohort was defined by selecting all records from the NSW Admitted Patient Collection or ABS Mortality Data with and an ICD code indicating intentional self-harm. The CheReL linked records from the cohort to records from the NSW Emergency Department Data Collection, and the NSW RBDM death data.

Attempted suicide is a major public problem; it occurs much more frequently than completed suicide and often leads to substantial physical injury and high emotional and economic costs. Thus, an understanding of method substitution effects among suicide attempters (who, as a group, are at very high risk of completed suicide) has potential to yield valuable information for suicide prevention initiatives.

Back to top

Establishing the factors that contribute to a shortfall in evidence-based radiotherapy. Prof Geoff Delaney, Liverpool Hospital and University of NSW

Previous studies by this research group indicate that 52% of all cancer patients should receive at least one course of radiotherapy during their illness.
In NSW however, 37% of all cancer patients receive radiotherapy annually, suggesting that there is a significant shortfall between what is considered optimal and what is actually delivered.

The current study aims to establish and analyse a state-wide database linking radiation oncology records from each NSW Radiation Oncology Department to the NSW Central Cancer Registry data. This will enable a better understanding of the areas of greatest shortfall, characterisation of under–served groups, identification of possible issues that might need to be addressed to improve the uptake of radiotherapy, and more rigorous assessment of our model of optimal radiotherapy utilisation, particularly where discrepancies between our "ideal model of care" differs substantially from current practice.

Back to top

Investigating best practice primary health care for older Australians with diabetes using record linkage. Associate Professor Elizabeth Comino, University of New South Wales

In Australia most people access health care through community based primary care settings such as general practice, community health services, pharmacy, and allied health. In these settings care is fragmented due to the range of health professionals involved, mix of private and public funding and practice, number of stakeholders with funding responsibility, and mix of fee-for-service and salaried staff. Because there is no comprehensive source of data on service use in this setting, primary health care is underrepresented in health statistics, and there has been limited exploration of processes of care for people with chronic health care needs.

Data linkage presents an opportunity to explore the processes of primary health care across settings using record linkage. This study aims to describe the process of primary health care provision for older people with diabetes; identify the predictors of primary health care provision; and explore the relationship between primary health care and health outcomes including quality of life and hospitalisation. The CHeReL linked records from the 45 and Up Study, including Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data, to the NSW Admitted Patient Data Collection, the NSW Emergency Department Data Collection, and the NSW RBDM death registrations. A sub study nested within the 45 and Up Study will also be undertaken to validate self-reported diabetes.

Findings will enable examination of the reach of incentives to improve primary health care provision to patients with diabetes and the impact of improved care on outcomes such as hospitalisation. It will provide important insight into the relationship between clinical care in community based settings and outcomes such as hospitalisation. It will also inform strategies to integrate primary health care across state and national jurisdictions and support more effective access to multidisciplinary care for people with chronic conditions.

Back to top

Incidence of blood borne viruses and cancer and related mortality among opioid dependent persons in pharmacotherapy. Associate Professor Claire Vajdic, University of NSW

Opioid-dependent persons in pharmacotherapy in NSW have an excess rate of death due to cancer, but little is known about cancer incidence or the role of blood-borne viruses in risk of cancer or death. This study will use linked data from the NSW Pharmaceutical Drugs of Addiction System, the National Death Index (NDI), Australian Cancer Database (ACD), NSW Notifiable Conditions Information System, National Aids Registry and the National HIV database to investigate cancer and blood borne virus (hepatitis, HIV) incidence among treatment-seeking opioid dependent persons in NSW. This knowledge will allow the development of appropriate interventions and prevention strategies in this vulnerable and marginalised population. A second aim of this study is to quantify the sensitivity and specificity of name-code versus full-name data linkage to the NDI and ACD, the results of which will inform the interpretation of future health data linkage based on name-coded records.