

Centre for Health Record Linkage

THE FIRST THREE YEARS
2006–07 TO 2008–09

August 2009



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Foreword

The Centre for Health Record Linkage (CHReL) was established in 2006 to provide high quality record linkage services for research to benefit the people of NSW and the ACT.

In its first three years of operation the CHReL has made some outstanding achievements:

- The CHReL Master Linkage Key now contains over 26 million records relating to more than six million people; and is the largest resource of its type in Australia.
- The CHReL provided 57 linkage services to support research projects and projects carried out by the NSW and ACT health systems.
- The CHReL infrastructure has supported projects that have attracted \$3.9 million in research funds from the National Health and Medical Research Council.

Critical to this success has been the support of nine organisations: ACT Health, the Cancer Institute NSW, the NSW Clinical Excellence Commission, the NSW Department of Health, The Sax Institute, the University of New South Wales, the University of Newcastle, the University of Sydney and the University of Western Sydney. These organisations provided both funding support and strategic and operational advice through the CHReL Management Committee.

Importantly, the CHReL's achievements have been made by implementing best practice in privacy preserving record linkage, an approach which has been strongly supported by organisations that are custodians of health records, human research ethics committees, researchers, and the community.

This report summarises the work carried out by the CHReL in its first three years. I look forward to collaborating with all our stakeholders in building on this work into the future.



Sarah Thackway

Chair
CHReL Management Committee

Introduction

The Centre for Health Record Linkage (CHeReL) was established in July 2006 by a collaboration of ACT Health, the Cancer Institute NSW, the NSW Clinical Excellence Commission, the NSW Department of Health, The Sax Institute, the University of New South Wales, the University of Newcastle and the University of Sydney. The University of Western Sydney became a Member of the CHeReL in July 2008. The Cancer Institute NSW is the host organisation for the CHeReL and is responsible for employment of staff and operational aspects of the CHeReL.

Mission

The mission of the Centre for Health Record Linkage (CHeReL) is:

To create and sustain a record linkage infrastructure for the health and human services sector, and provide access to these resources to bona fide researchers and health planners and policy makers.

Objectives

The CHeReL provides high quality record linkage services to:

- facilitate research that may contribute to the promotion, protection and maintenance of the health of the public
- facilitate the planning, evaluation and delivery of health services
- contribute to knowledge regarding research methods relating to health data collection, linkage of health-related data and compilation and use of health related statistics generally
- allow the outcomes of activities related to the above objects to be available for the benefit of the public and to contribute to knowledge on an open and equitable basis.

CHeReL Strategic Plan 2006–07 to 2008–09

For the first three years, the CHeReL Strategic Plan covered four strategic domains:

- Deliver high quality record linkage services.
- Serve the public interest in use of health data and protect privacy.
- Engage stakeholders.
- Ensure good governance.

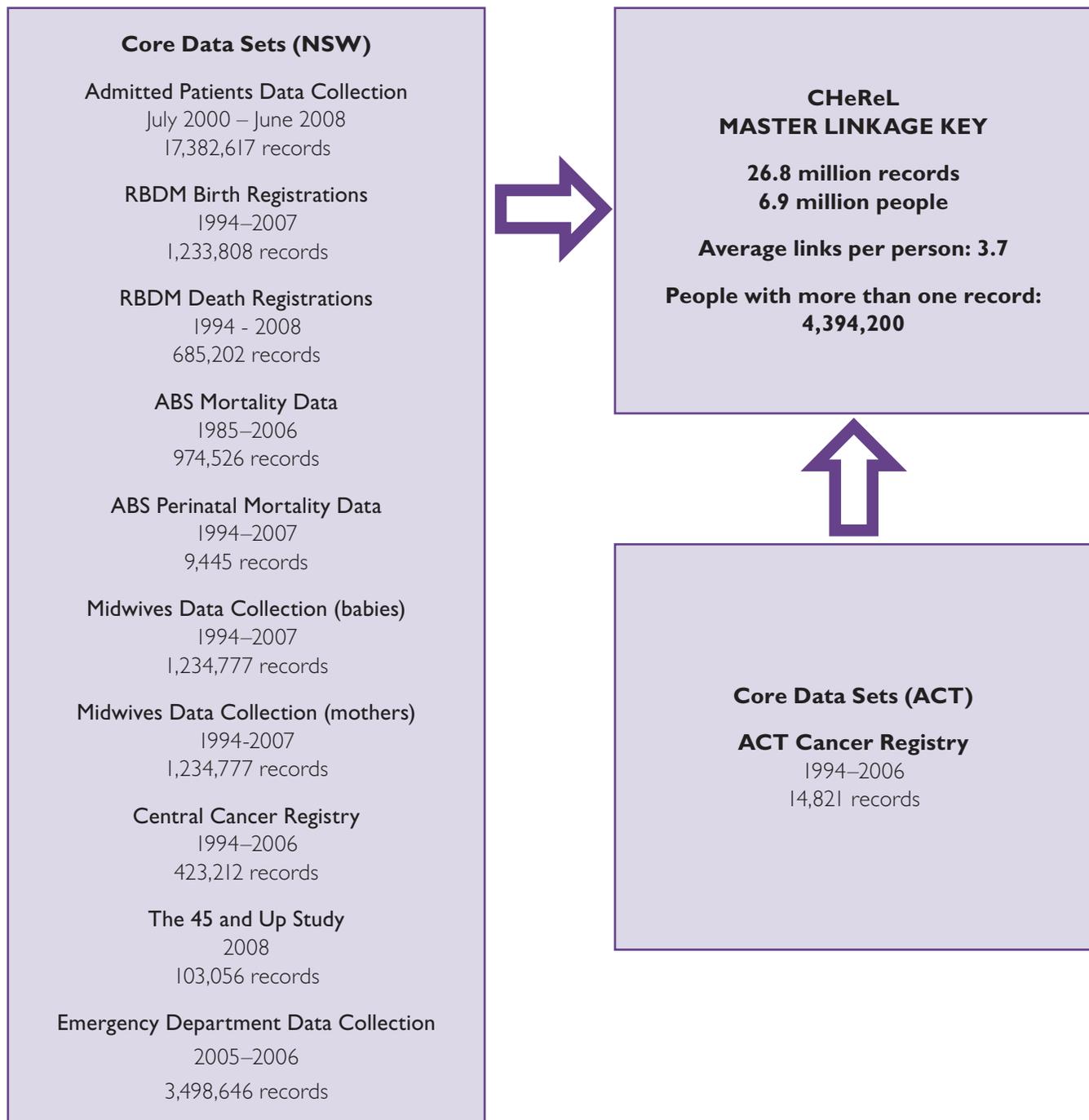
This report describes the progress made by the CHeReL against these strategic objectives.

Strategic Objective I

Deliver high quality record linkage services

In the first three years, the CHReL has established a Master Linkage Key of more than 26 million records. The Master Linkage Key enables timely, cost-effective access to millions of records from population-based data collections that are most commonly used by researchers. It is supported by a high performance data management system and record linkage procedures that maintain linkage error rates below 0.5 per cent. The CHReL Master Linkage Key is now the largest infrastructure of its kind in Australia.

CHReL Master Linkage Key, 30 June 2009



In addition to the establishment of the Master Linkage Key, 57 record linkage projects were completed over the three-year period and another 30 were in progress at June 2009. Individual reports of linkage methods, error rates and results were provided to researchers for every linkage project. To date, four scientific papers using data from the CHeReL have been published. More information on these early research outputs and completed linkage projects is available in **Appendix I**.

The CHeReL is involved in record linkage research and development. The following projects have been carried out or are currently underway:

- Development of criteria for checking false positive links in the Master Linkage Key.
- Investigation of procedures and methods to reduce clerical review rates without affecting linkage quality.
- Comparison of linkage methods for use with limited identifiers.

Opportunities to carry out linkage projects with human services data held by other government agencies have been explored, with interest expressed by several agencies. Linkages have been carried out using data from the NSW Bureau of Crime Statistics and Research, the NSW Department of Ageing, Disability and Home Care and the NSW Department of Corrective Services.

Strategic Objective 2

Serve the public interest in use of health data and protect privacy

In order to ensure that the public interest in use of health data is served, the CHeReL has:

- established procedures to ensure compliance with privacy laws in relation to collection, use and disclosure of personal information
- ensured that all record linkage projects are approved by the data custodians and the relevant human research ethics committee
- consulted with the Office of the NSW Privacy Commissioner and the Office of the Privacy Commissioner (federal) in relation to the CHeReL's governance, policies and procedures
- established the CHeReL Community Advisory Committee.

Strategic Objective 3

Engage stakeholders

Stakeholder engagement – including data custodians, ethics committees, researchers and the community – has been critical to the successful operation of the CHReL in its first three years.

Data custodians have developed a strong working relationship with the CHReL, particularly those custodians who supply data for the Master Linkage Key. Data custodians must approve all record linkage projects involving datasets for which they are responsible. Procedures for encryption and secure transfer of data to and from the CHReL have been implemented.

All linkage projects involving two or more data collections must be approved by the relevant human research ethics committee. For data owned by the NSW Department of Health or for access to the Master Linkage Key, approval of the NSW Population and Health Services Research Ethics Committee (PHSREC) is required. The CHReL has developed a very close working relationship with the PHSREC, which has enabled the CHReL to provide appropriate advice on ethical issues in record linkage to researchers as they develop their project proposals.

In the first three years, four universities were represented on the CHReL Management Committee. Researchers therefore had direct involvement in the development of the CHReL's Strategic and Business Plans, and relevant policies such as the Charging Policy for CHReL services. The CHReL website includes information for researchers including a Guide to the CHReL Record Linkage Services. CHReL staff have attended meetings with researchers to discuss projects and advise on procedures for obtaining approval for record linkage projects. The CHReL has established a part-time position for a research project manager, dedicated to supporting each researcher through the application process and advising on the development of linkage studies. The CHReL has supported the development of a new unit of study, Introductory Analysis of Linked Data, which will be offered annually at the School of Public Health, Faculty of Medicine, University of Sydney.

Members of the Community Advisory Committee are appointed following open advertisement. The Committee has met regularly during the first three years, providing advice on communication strategies and plans, complaints handling, CHReL plans, policies and procedures and other issues of relevance to the community.

The CHReL website contains information of interest to community members, including information on governance and research studies that have used linked data. In the first three years, the CHReL has carried out two mail campaigns to distribute information about the CHReL's establishment, purpose and privacy protocols to community, professional and privacy organisations. The most recent newsletter is available on the CHReL website.

The CHReL has conducted a total of 42 presentations and events at conferences, workshops and forums in the past three years, covering a range of audiences from researchers, data custodians, privacy groups, clinicians and health policy makers.

Strategic Objective 4

Ensure good governance

Over the first three years, the CHeReL Management Committee and Community Advisory Committee formed the governance of the CHeReL. The Management Committee comprised representatives of organisations that were funding members of the CHeReL and the Chair of the CHeReL Community Advisory Committee. The Management Committee met regularly and provided expert guidance to the CHeReL on strategic and operational matters.

Over the three years the following policies were developed: charges for services, response to a breach of conditions by a researcher, response to complaints and response to a subpoena. In addition, procedures for access to services, and procedures to ensure physical and electronic security of data were developed. An IT risk assessment and an independent review were carried out in the third year.

Progress has been made towards establishing record linkage as a recognised and valued tool in population health research in NSW. Over the first three years there have been five NHMRC grants awarded to researchers using CHeReL Services, attracting \$3.9 million in research funds to NSW. Demand for linked data has been increasing. The number of linkage requests completed by the CHeReL has increased from four in 2006–07 to 18 in 2007–08 and 35 in 2008–09.

The CHeReL is participating in the National Collaborative Research Infrastructure Strategy Population Health Research Network (NCRIS PHRN). The NCRIS PHRN will enable linked data from several states and territories to be combined for approved research projects and will further improve the availability and ease of accessing linked data in NSW and the ACT.

A review of the CHeReL's business model was initiated in August 2008. The original model provided for member organisations to receive up to 80 per cent of their funding contribution back in free services, referred to as linkage credits. The model was intended to attract and commit major supporting members and encourage the use of linked data through inexpensive access. While these objectives were largely achieved, the review identified accumulating liabilities for free services as a threat to CHeReL's sustainability. It recommended changes to member entitlements, particularly the conversion of linkage credits to unlimited access to the MLK infrastructure, which member contributions had contributed to creating and could be provided at comparatively low cost. These changes reduced the liability associated with unused linkage credits, form the basis of a sustainable model for the next phase and create stronger incentives for researchers to use the available resource.

An independent review of the CHeReL was also carried out in October 2008. The review concluded that the CHeReL has been enormously successful in completing its set up in a very short time. It has broad and growing usage among its stakeholders, appreciation of its capabilities and growing awareness of its services. The recommendations of the review provide a strong basis for the next phase of the CHeReL's development as it continues to develop its record linkage infrastructure to support research and evaluation.

Appendix I

Early Research Outputs

To date, four scientific papers using data from the CHReL have been published:

1. *Hadfield RM, Lain SJ, Raynes-Greenow CH, Morris JM, Roberts CL. 'Is there an association between endometriosis and the risk of pre-eclampsia? A population based study.' Human Reproduction 2009; 24: 2348-52.*

Endometriosis affects up to one in 10 women of reproductive age, and small studies (eg. 250 women in each group) have reported evidence that women with endometriosis may have a reduced risk of pre-eclampsia. To investigate with a much larger population CHReL linked 2000-2005 data for NSW births (the NSW Midwives Data Collection) with data on hospital admissions (the NSW Admitted Patient Data Collection), including all women aged from 15 to 45 years of age with a single child pregnancy (approx. 3,200 women in the endometriosis group and 205,000 in the no-endometriosis group). After adjusting for confounders the study found no evidence for a higher rate of pregnancy hypertension or pre-eclampsia in women with severe endometriosis, or endometriosis in conjunction with infertility, compared to those with no endometriosis. However it did reveal that 1.6% of women had received a surgical diagnosis of endometriosis before the birth of their first child (the first such frequency estimate). Linked population-based data are a potentially valuable resource for verifying findings from small clinical studies.

2. *Stavrou EP, Baker DF, Bishop JF. Maternal smoking during pregnancy and childhood cancer in New South Wales: a record linkage investigation. Cancer Causes Control 2009 July 16 [Epub ahead of print].*

Maternal smoking during pregnancy has been associated with low birth weight, preterm delivery, and childhood asthma, but the effect on childhood cancer risk has been unclear. To investigate a linkage was conducted between the NSW Central Cancer Registry (CCR) and the NSW Midwives Data Collection, assessing NSW children born between 1994 and 2005. After adjusting for possible contributory factors, no overall association between maternal smoking and childhood cancer was found. However a significant association was found between maternal smoking and childhood retinoblastoma (as well with preterm birth and low birth weight). This is the first time an association between maternal smoking and childhood retinoblastoma has been reported. Further investigation is needed to ensure that the observed association did not occur by chance and to rule out alternative explanations (eg. poor living conditions), but data linkage has the potential to identify potentially causal factors for low frequency conditions.

3. *Lain SJ, Algert CS, Tasevski V, Morris JM, Roberts CL. Record linkage to obtain birth outcomes for the evaluation of screening biomarkers in pregnancy: a feasibility study. BMC Medical Research Methodology 2009, 9:48.*

Predictive tests are typically evaluated through individual interviews or medical records reviews. An alternative approach is to use record linkage. This study linked information on maternal serum levels from a New South Wales pathology database (The Pacific Laboratory Medicine Services or PaLMs) with data from routinely collected birth and hospital databases (The Midwives' Data Collection or MDC, and the Admitted Patient Data Collection or APDC). The linkage provided pregnancy outcomes for almost 90% of the total sample of women (1882) included in the study, and analysis revealed that the biomarker PAPP-A had a stronger association with adverse pregnancy outcomes (preterm delivery, low birth weight, and foetal loss or stillbirth) than the biomarker free β -hCG, consistent with the findings of published studies that used traditional methods. Predictive tests can be evaluated by linking pathology databases with routinely collected population health databases, with the advantages of being less expensive, avoiding bias associated with interviewers and patient recall, and not needing to infringe patient privacy.

4. *New South Wales Mothers and Babies Report 2006, NSW Public Health Bull 2007; 18(S1): 1-136*

This report on mothers and babies in NSW is published annually by the NSW Department of Health. The report includes information on recent trends in births, births in individual hospitals, Aboriginal mothers and babies, mother's country of birth, and causes of death among newborn babies.

Reports on Population Health Surveillance

The health of the people of New South Wales 2008 - Report of the Chief Health Officer Available at: www.health.nsw.gov.au/publichealth/chorepl/.

The Report of the Chief Health Officer, a flagship publication of the NSW Department of Health, provides an overview of key population health indicators, health inequalities, emerging health priorities and new health data sources

Laws PJ, Abeywardana S, Walker J & Sullivan EA. Australia's mothers and babies 2005. Perinatal statistics series no. 20. Cat. No. PER 40. Sydney: AIHW National Perinatal Statistics Unit, 2007.

This report on mothers and babies in Australia uses data linked by the CHeReL, in addition to other sources, in order for information on marital status, insurance status and postnatal length of stay to be reported.

Other Research Using Data linked by the CHeReL

The PRISM Study: A Program of Research Informing Stroke Management in NSW

This program of research is led by Dr Melina Gattelari from the University of New South Wales with collaborators from Sydney South West Area Health Service. Overall the research program is intended to assess the current management of stroke in NSW and identify future initiatives for improving health service delivery and patient care. *The CHeReL has provided linkage services on four occasions to support this program of research.*

Comprehensive linkage of maternal and infant health data for monitoring health outcomes and planning of maternity services in NSW

Dr Christine Roberts, Kolling Institute of Medical Research, University of Sydney with collaborators from the NSW Department of Health.

This program of research aims to make a complete assessment of maternity care services in NSW for births 1994-2010 up to one year after birth. The aims are 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 CHReL has provided linkage services on six occasions to support this program of research.*

Linkage of the NSW Inpatient Statistics Collection with data on deaths held by the NSW Registry of Births, Deaths and Marriages and the Australian Bureau of Statistics to provide a means of examining outcomes of hospital health care in NSW

Lee Taylor and collaborators from the NSW Department of Health.

This project enables NSW Health to make linked de-identified data available to staff employed by the public health system through the Health Outcomes Information and Statistical Toolkit (HOIST) system, a state-wide data warehouse network. The linked data are used for a variety of purposes including research into and evaluation of: patterns and trends in end-of-life health care use and cost; patterns of readmission and mortality associated with particular medical conditions and procedures; and the effectiveness of health care services in reducing preventable mortality and morbidity (eg. readmissions) in NSW. *The CHReL has provided linkage services on three occasions to support this project.*

International Study of Long Term Hazards of Radiotherapy for Breast Cancer

This study is being carried out by the Oxford University Department of Epidemiology and includes data from more than 50 cancer registries that meet standards of the International Association of Cancer Registries (IACR). Data linkage by the CHReL allowed the participation of the New South Wales Central Cancer Registry (NSW CCR) in this study.

The 'Drive Study': Cohort Study of Risk Factors for Young Driver Injury

Associate Professor Rebecca Ivers, George Institute with collaborators from the George Institute, University of New South Wales, Roads and Traffic Authority of NSW, University of Western Australia, Royal Alexandra Hospital for Children Westmead and Victoria University.

An analysis of the usefulness of the linked Central Cancer Registry-Inpatient Statistics Collection for examining patterns of care of people with prostate, lung, breast and colorectal cancer.

Associate Professor Dianne O'Connell with collaborators from the Cancer Council NSW.

Morbidity in people with hepatitis B and C in New South Wales

Heather Gidding, National Centre in HIV Epidemiology and Clinical Research (NCHECR) with collaborators from NCHECR and the NSW Department of Health.

Age, acculturation and mental health among overseas-born residents of NSW

Professor Louisa Jorm, University of Western Sydney (UWS) and collaborators from UWS and the Sydney South West Area Health Service.

An analysis of the usefulness of the linked Central Cancer Registry-Inpatient Statistics Collection for examining patterns of care of people with thyroid and pancreatic cancer

Associate Professor Dianne O'Connell with collaborators from the Cancer Council NSW.

Assessment of the effectiveness of a community based faecal occult blood screening program for colorectal cancer

Dr Martin Veysey, Northern Sydney Central Coast Area Health Service, with collaborators from Rotary Bowelscan, the Cancer Institute NSW and the Northern Sydney Central Coast Area Health Service.

Optimal strategies to be used when linking datasets that contain a Statistical Linkage Key

Sanja Lujic, University of Western Sydney, with collaborators from the Centre for Health Record Linkage, the Sax Institute and the NSW Department of Health.

Ongoing cross-checking of the State Tuberculosis (TB) Office database against the Notifiable Diseases Database

Dr Jeremy McAnulty and collaborators from the NSW Department of Health.

Temporal trends in the epidemiology of infective endocarditis in NSW

Dr Raymond Sy, University of Sydney, with collaborators from Concord Repatriation General Hospital.

Alcohol use in pregnancy

Dr Lucy Burns and collaborators from the National Drug and Alcohol Research Centre, the University of New South Wales.

Association between maternal smoking during pregnancy, birth outcomes and the risk of childhood cancer

Dr Efty Stavrou and collaborators from the Cancer Institute NSW

Best practice procedures and associated outcomes in oesophageal, liver, pancreas and stomach cancer

Professor James F Bishop, Cancer Institute NSW, with collaborators from the Cancer Institute NSW and North Shore Private Hospital.

Improving birth statistics in New South Wales

Professor Richard Madden, National Centre for Classification in Health (NCCH), University of Sydney, and collaborators from the NCCH and Perinatal and Reproductive Epidemiology Research Unit, University of New South Wales.

The role of maternal cancer history in the occurrence of stillbirth and birth defects

Dr Efty Stavrou and collaborators from the Cancer Institute NSW.

An examination of the quality and validity of mothers and babies coded data found in administrative datasets – through linking NSW Admitted Patient Data Collection (APDC) with Midwives Data Collection (MDC) and Registry of Births, Deaths and Marriages (RBDM) birth registration data.

Dr Mary KP Lam and collaborators from the National Centre for Classification in Health (NCCH), University of Sydney.

Quality of life, physical and emotional health in mid & older survivors of cancer

Dr Efty Stavrou and collaborators from the Cancer Institute NSW.

Patterns of hospital health service utilisation for heart failure patients in NSW

Dr Jane Robertson, Department of Clinical Pharmacology, University of Newcastle, with collaborators from the University of Newcastle, University of New South Wales and Institute for Clinical Evaluative Sciences.

Validation study of recurrent postpartum haemorrhage and associated factors as reported in the Admitted Patient Data Collection and Midwives Data Collection (validated against medical records)

Dr Christine Roberts, Kolling Institute of Medical Research, University of Sydney with collaborators from the University of Sydney and NSW Department of Health.

Defining immune dysregulation cohorts at risk of cancer

Dr Claire Vajdic, Prince of Wales Clinical School Faculty of Medicine, the University of New South Wales with collaborators from NCHECR, University of New South Wales, Western Australian Institute for Medical Research and Concord Repatriation General Hospital.

A pilot study investigating the ability of maternal levels of Angiotensin 2 (Ang-2) in early pregnancy to predict adverse outcomes. A novel investigative approach utilising routinely collected health data

Dr Christine Roberts with collaborators from the Kolling Institute of Medical Research.

Australian HIV Observational Database Hospitalisation Linkage Project

Associate Professor Matthew Law, National Centre in HIV Epidemiology and Clinical Research (NCHECR), The University of New South Wales with collaborators from NCHECR, the Carlton Clinic, the Alfred Hospital, Royal Perth Hospital and Murdoch University.

The 45 and Up Study: exploring met and unmet needs for home and community care in NSW

Professor Louisa Jorm, University of Western Sydney (UWS) with collaborators from UWS, the University of Sydney and University of Newcastle.

Descriptive epidemiology of stillbirth

Associate Professor Heather Jeffery and collaborators from the Royal Prince Alfred Hospital and University of Sydney.

The 45 and Up Study: Data Linkage Component (Death Matching)

Associate Professor Emily Banks, Australian National University and Sax Institute with collaborators from the Cancer Council NSW, University of Sydney, Northern Rivers University, University of Oxford, the University of Newcastle, Royal Prince Alfred Hospital, Western Sydney Area Health Service, the University of New South Wales and the NSW Department of Health.

The impact of hospital based aged care and dementia services on outcomes for people with dementia admitted to hospital - a regional analysis

Professor Diane Gibson, University of Canberra with collaborators from the University of New South Wales, Australian Institute of Health and Welfare, University of Queensland, University of Sydney, La Trobe University and Alzheimer's Australia.

Post-discharge outcomes of older patients hospitalised with acute illness

Dr David Basic and collaborators from Liverpool Hospital Sydney South West Area Health Service.

Mothers and gestation in custody - data linkage study of birth and neonatal outcomes of women in prison during pregnancy

Associate Professor Elizabeth Sullivan, Australian Institute of Health and Welfare and The University of New South Wales, with collaborators from the University of Sydney, Royal Hospital for Women and University of Technology Sydney.

Mental Illness and Substance Use - impact on birth and neonatal outcomes

Associate Professor Elizabeth Sullivan, Australian Institute of Health and Welfare and The University of New South Wales with collaborators from the University of New South Wales.

Exploring the contributions of individual-, area- and service-level factors to Indigenous health outcomes

Professor Louisa Jorm, University of Western Sydney with collaborators from the Medical Research Council (UK), NSW Department of Health, the Sax Institute, Baker Heart Research Institute and the University of Western Sydney.

Linkages to Support Routine Reporting and Data Quality Improvement / Development

Database De-duplication and Data Quality Improvement/Development

The CHReL has completed nine linkages to enable de-duplication of the following databases:

NSW Notifiable Diseases Database

NSW Midwives Data Collection

NSW Birth Defects Register

NSW Central Cancer Registry

NSW Perinatal Death Review Database

A comparison of the scope and data in the CCR, Clinical CR and APDC data collections to inform the development of the NSW Cancer Registry Program.

Professor James F Bishop, Cancer Institute NSW with collaborators from the Cancer Institute NSW and the Sydney South West Area Health Service.

Reporting

The CHReL has carried out 2 linkages for the Cancer Institute NSW to support the operations of BreastScreen NSW and to allow BreastScreen NSW to meet requirements for reporting interval cancers.

The CHReL has carried out 2 linkages for NSW Health to support the reporting of Aboriginality for the NSW Mothers and Babies report.



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