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## Inside this issue:

Master Linkage Key	1
Collaboration of	1
Recent Events	1
Website Updates	1
Recent Linkage Projects	2
Staff	2
Contact Us	2

## Recent Events

### *Researcher Forum*

21 August 2008  
9.00am – 1.00pm  
Rydges Lakeside,  
Canberra

## Website Updates

- > *Data Custodian Information Pack*
- > *Guide to CHeReL Health Record Linkage Services v1.3*
- > *CHeReL Quality Assurance in Record Linkage*
- > *Statistics and information on the Master Linkage Key*

Presentations given at the forums including projects that have used data linkage can be viewed on the web via the CHeReL website under Events.

[www.cherel.org.au](http://www.cherel.org.au)

## Welcome

Welcome to the first issue of the Centre for Health Record Linkage (CHeReL) Newsletter. This year has been very busy for the CHeReL staff. We have given many talks at conferences and meetings, to researchers and others, about the CHeReL's work. The CHeReL enables research using linked health records to be carried out in a way that preserves privacy and also allows the information to be used to benefit the community and to support health services in NSW and the ACT.



Centre for Health Record Linkage staff

The CHeReL now has a Master Linkage Key that points to over 20 million health and health-related records held in databases owned by the NSW Department of Health, the Registry of Births, Deaths and Marriages, the Sax Institute and the Cancer Institute NSW. These records can be used to support research subject to the approval of a human research ethics committee and the organisations that own the source databases. So far this year we have completed 20 record linkage projects for a wide range of organisations including the University of Sydney, the University of NSW, the NSW Department of Health, the Cancer Institute NSW and the Cancer Council NSW.

The CHeReL provides record linkage services for bona-fide research and to assist the public health system to monitor the quality of health services provided to the community. The CHeReL operates in compliance with privacy laws and ethical guidelines established by the National Health and Medical Research Council. We have established quality control procedures that ensure that records held by the CHeReL are secure; and also that the quality of the record linkage services the CHeReL provides is high.

## Master Linkage Key

There are currently 20.6 million records in the CHeReL Master Linkage Key, representing approximately six million people. Once data custodian and ethics committee approval is obtained, the CHeReL uses information such as name, date of birth and address to create the Master Linkage Key that points to where records for a person can be found in different health databases. Information about people's health does not go to the CHeReL, but is held in the original database. Researchers must obtain separate data custodian and ethical approval for each project they carry out.

The CHeReL does not provide linked data directly to researchers. The CHeReL creates a series of numbered 'project keys' that provide a mechanism for data custodians to provide data with personal identifiers removed to researchers for an approved research project.

**20.6 million records  
now in the  
Master Linkage Key**

The Master Linkage Key currently includes pointers to records of hospital admissions, emergency department attendances, births, deaths and cancer registrations in NSW. More information on the Master Linkage Key and other record linkage services provided by the CHeReL can be found on the CHeReL website at: <http://www.cherel.org.au>.

### ***The Centre for Health Record Linkage is a collaboration of:***

ACT Health, Cancer Institute NSW (the host organisation), NSW Clinical Excellence Commission, NSW Department of Health, The Sax Institute, The University of Newcastle, The University of New South Wales, The University of Sydney and The University of Western Sydney.

# Recent Linkage Projects

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## **Validity of routinely collected data for monitoring patterns of cancer care**

**Organisation:** *Cancer Council NSW*

**Principal Investigator:** *A/Prof Dianne O'Connell*

Patterns of cancer care studies are important for assessing and monitoring the treatment received by cancer patients. However data collection for each type of cancer can be very time-consuming and resource-intensive. The aim of this study was to ascertain whether patterns of cancer care can be accurately captured through the linkage of records in the NSW Central Cancer Registry and the NSW Department of Health's Admitted Patient Data Collection. These data were linked to databases of treatment information collected directly from doctors in the Cancer Council's patterns of care studies for colorectal, lung and prostate cancer. If the patient-level comparisons indicate that the administrative data are accurate, then it may be possible to replace some types of patterns of care studies with record linkage studies, allowing studies to be conducted for all of NSW on a regular and ongoing basis.

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

**Organisation:** *Cancer Institute NSW*

**Principal Investigator:** *Dr Efty Stavrou*

This study aims to find out if there is any association between maternal smoking during pregnancy and cancer developing in the child. The study is using linked records from the Central Cancer Registry and the NSW Midwives Data Collection. The NSW Midwives Data Collection is a database of all births in NSW and is maintained by the NSW Department of Health.

## **The Drive Study**

**Organisation:** *The George Institute*

**Principal Investigator:** *Dr Rebecca Ivers*

The George Institute is carrying out a study of risk factors for young driver injuries in NSW. Over an 18 month period (June 2003-December 2004), all new drivers aged 17-24 years in NSW were mailed a letter inviting them to join the study. Participants completed a questionnaire and were asked to consent to linkage of their survey information with information on traffic offences, traffic crashes and injuries occurring within 2 years of obtaining their license. Information for the project mailing list was obtained from the Roads and Traffic Authority Licensing Database. Information on offences and crashes was obtained from the Roads and Traffic Authority Traffic Accident Database System. Information on injuries was obtained from the NSW Department of Health Emergency Department Data Collection and Admitted Patient Data Collection. Record linkage of survey and Department of Health Data was carried out by the CHeReL. The survey data were linked

to the Roads and Traffic Authority datasets using participants' licence numbers. The analysis for the project is currently underway.

## **Prediction of adverse pregnancy outcomes**

**Organisation:** *Kolling Institute, University of Sydney*

**Principal Investigator:** *Dr Christine Roberts*

Information on antenatal screening tests in the first three months of pregnancy was obtained from a pathology database at Royal North Shore Hospital for 2,000 randomly selected women. Pregnancy outcome information for these women has been obtained by linkage with the NSW Midwives Data Collection and the NSW Admitted Patient Data Collection. This study aims to determine whether antenatal serum screening will be able to predict certain pregnancy outcomes including: fetal growth restriction (when a baby fails to grow properly in the uterus), miscarriage, premature birth, stillbirth, neonatal death, and admission to neonatal intensive care.

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

**Organisation:** *National Centre in HIV Epidemiology and Clinical Research*

**Principal Investigator:** *Ms Heather Gidding*

This study aims to provide information on rates of hospitalisation among people with hepatitis B (HBV) and C (HCV) and the relationship of this burden of disease with HIV co-infection. The study uses linked records on notified cases of HBV and HCV from the NSW notifiable diseases data base with HIV and AIDS notification data and records from the NSW Admitted Patient Data Collection. The study will provide knowledge about the current burden of these diseases in Australia and support appropriate planning of hospital services. It will also provide baseline data to measure the potential impact of future treatment and prevention strategies.

## **Age, acculturation and mental health among overseas-born residents of New South Wales**

**Organisation:** *University of Western Sydney*

**Principal Investigator:** *Prof Louisa Jorm*

Linked records of the NSW Emergency Department Data Collection (EDDC), the NSW Admitted Patient Data Collection (APDC), and Registry of Births Deaths and Marriages (RBDM) death records are being used to assess: first, whether patterns of health service use for mental health problems vary according to country of birth; and second, whether patterns of service use for mental health problems among overseas-born people vary with age and according to interpreter required and preferred language (APDC), need for interpreter service (EDDC) and period of residence in Australia (RBDM death records). Through the participation of Sydney South West Area Health Service as a partner in this project, the study findings will be used directly for the planning of services to sustain the mental health and wellbeing of the culturally diverse population of greater western Sydney.

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## Staff

- Katie Irvine (Manager)
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