

No.2 November 2009

Inside this issue:

What's New	1
Population Health Research Network	1
Community Advisory Committee	1
Master Linkage Key	1
Recent published studies	2
Published reports	2

Website Updates

The following are available from the Downloads section of the CHeReL website

- > *Report on the first three years of the CHeReL*
- > *CHeReL Governance 2009-10 to 2011-12*
- > *Summary of validation studies carried out on NSW Department of Health data collections*
- > *Master Linkage Key Information on databases included in the Master Linkage Key and the number of records from each database*
- > *Quality assurance in record linkage*

What's New

From 1 July 2009, the Cancer Institute NSW and the NSW Department of Health entered into a new funding agreement to support the continued operation of the CHeReL for 2009-10 to 2011-12. Previous Member organisations were invited to rejoin the CHeReL. Organisations that support the aims of the CHeReL are welcome to join the CHeReL as funding Members.

In the past year the CHeReL has supported more than 30 linkage projects across a range of fascinating subjects. Data Linkage by CHeReL hit headlines earlier this year when new research by the Cancer Institute NSW provided the strongest indication yet that smoking during pregnancy increases a child's likelihood of developing cancer (see page 2).

Population Health Research Network NSW ACT

The Population Health Research Network (PHRN) is a program funded jointly by the National Collaborative Research Infrastructure Strategy (NCRIS) and state and territory governments. The NSW and ACT component of the PHRN (PHRN NSW ACT) will design and build infrastructure to support approved health research projects that involve record linkage. The infrastructure will support secure exchange, storage and analysis of research data; and will provide a central source of information about health databases, how to carry out research using linked data, and other information that will help researchers with their projects. The Sax Institute has been appointed as the organisation responsible for managing the project in NSW and ACT. The CHeReL is a key stakeholder in the project and the project team will be working closely with the CHeReL. The CHeReL Community Advisory Committee will provide advice on matters of community interest in the project. Further information is available from Coralie Le Nevez, Project Manager PHRN NSW ACT on 02 9514 5946 or email to Coralie.LeNevez@saxinstitute.org.au.

Community Advisory Committee

The CHeReL Community Advisory Committee was established in early 2007 and provides advice to the CHeReL Manager on issues of community interest in the operation of the CHeReL, including: a communication strategy for information to be provided to the community; procedures for responding to complaints from the community or other concerns that may be raised by the community; whether proposed projects are likely to be in the public benefit or not, where this is not immediately clear; the strategic and business plans of the CHeReL; policies and procedures of the CHeReL; any other issues that are of concern to the Community Advisory Committee members. The Committee meets three times per year. Expressions of Interest for NSW and ACT members were advertised in June 2009, and the CHeReL recruited two new members.

Current members of the committee are Professor Tony Adams (Chair), Dr Terry Beed, Ms Margo Gill, Ms Liz Hay, Mr Tom Kelly and Ms Catherine Settle. The Committee would like to acknowledge the contribution of the late Geoffrey Hopkins and are saddened by his passing.

Master Linkage Key

The CHeReL Master Linkage Key (MLK) now contains about 28 million records, representing just over seven million people. The ACT Cancer Registry, the first of seven ethics approved ACT datasets was added to the MLK in April 2009. Information on the databases and number of records in the Master Linkage Key is updated regularly, see <http://www.cherel.org.au> for up to date information.

Recent published studies

Is there an association between endometriosis and the risk of pre-eclampsia? A population based study.

Hadfield RM, Lain SJ, Raynes-Greenow CH, Morris JM, Roberts CL.

Endometriosis is a common and often painful condition that may affect up to one in 10 women of reproductive age. Occurring when the tissue that lines the inside of the uterus is found outside the uterus (commonly on the fallopian tubes, ovaries, or the tissue lining the pelvis), its effects include pain and infertility.

A further common condition experienced by women is pre-eclampsia, affecting around five per cent of all pregnancies in Australia. Characterised by high maternal blood pressure, protein in the urine and fluid retention, in severe cases it may lead to kidney failure, liver failure, clotting problems or convulsions. One to two per cent of cases are severe enough to threaten the lives of both the mother and the unborn child.

Recent studies of relatively small groups (e.g. approximately 250 women in each of endometriosis and no-endometriosis groups) have reported finding evidence that women with endometriosis have a reduced risk of pre-eclampsia.

This study, which was carried out by researchers at the Kolling Institute at the University of Sydney, investigated this issue using a much larger population via a linkage conducted by the Centre for Health Record Linkage. Data for NSW births between 2000 and 2005 (from the NSW Midwives Data Collection) was linked with data on hospital admissions for a similar period (the NSW Admitted Patient Data Collection). All women aged from 15 to 45 years of age recorded with a single child pregnancy were included, and endometriosis was identified using ICD-10 codes. Approximately 3,200 women were in the endometriosis group, and over 205,000 in the no-endometriosis group.

In women with endometriosis diagnosed before their first birth, 10.9% had a diagnosis of pregnancy hypertension compared with 11.3% in women with no endometriosis diagnosis, a difference that was not statistically significant. There was also no evidence for a higher rate of pregnancy hypertension or pre-eclampsia when women with more

severe endometriosis, or endometriosis in conjunction with infertility, were compared to those with no endometriosis. Nor was there a difference after adjusting for maternal age and weeks gestation. The observation that 1.6% of women had received a surgical diagnosis of endometriosis before the birth of their first child is the first time the frequency of the disease in women of proven fertility has been reported.

It was concluded there was no evidence for an association between endometriosis and subsequent risk of either pregnancy hypertension or pre-eclampsia in the large population-based datasets. Longitudinally linked data are a valuable resource for verifying findings from small clinical studies in a large, population-based sample.

This study was published in the journal *Human Reproduction* in May 2009. For more information see <http://www.doi.org> (DOI name: 10.1093/humrep/dep123).

Maternal smoking during pregnancy and childhood cancer in New South Wales: a record linkage investigation.

Stavrou EP, Baker DF, Bishop JF.

A study of the association between mothers smoking in pregnancy and cancer in their children was carried out by the Cancer Institute NSW. Over one million records from the NSW Midwives Data Collection concerning babies born between 1994 and 2005 were linked to 948 childhood cancer records held by the NSW Central Cancer Registry.

Maternal smoking was found to be associated with low birth weight and premature birth in the baby. After taking into account a variety of factors, the study found that there was no difference in rates of childhood cancer overall between mothers who smoked and those who did not smoke during pregnancy. However, maternal smoking was associated with childhood retinoblastoma, a cancer that affects the retina of the eye.

The researchers concluded that awareness of the adverse effects of smoking in pregnancy on the baby should be highlighted to expectant mothers through antitobacco-smoking campaigns.

This study was published in the journal *Cancer Causes and Control* in July 2009.

Published reports

New South Wales Mothers and Babies Report

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

Using linked data of the NSW Midwives Data Collection (MDC), and the NSW Admitted Patient Data Collection, the 2006 Report found that Caesarean section and instrumental births (forceps and vacuum extraction) are more common among privately than publicly insured mothers. Among privately insured mothers the rate of normal vaginal birth fell from 54% in 2001 to 49% in 2005 and the caesarean section rate increased from 31% to 36% per cent. Among publicly insured mothers the rate of normal vaginal birth fell from 71% to 67% and the caesarean section rate rose from 20% to 24% over the same period.

The most recent NSW Mothers and Babies Report is for 2006 and is available on the Department of Health website at: www.health.nsw.gov.au/pubs/2009/mothers_babies.html.

The Health of the People of New South Wales—Report of the Chief Health Officer

The Report of the Chief Health Officer is published every two years by the NSW Department of Health.

By linking the NSW Admitted Patient Data Collection to itself, it is possible to know many hospital admissions occurred for various conditions, and also how many people were admitted to hospital with those conditions. These numbers may be different as some people are admitted to hospital more than once for the same condition.

For example, the Report found that in 2006-07, there were 54,212 admissions to hospital among 35,197 people for heart attack and angina; and there were 25,726 admissions among 15,468 people with diabetes as a main diagnosis. Similar information is available for asthma and chronic obstructive pulmonary disease (such as emphysema).

This information helps the Department of Health to both plan hospital services for the community and also to plan and evaluate prevention programmes.

The Report of the Chief Health Officer may be found on the Department of Health website at: www.health.nsw.gov.au.