Exploring the risk factors for disability using linked health data

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ASID 49th Annual Conference
7th November 2014
Overview

- Collecting information
- Data Linkage in WA
- Information preceding an adverse event
- Example of a study
- Benefits and limitations of data linkage
Collecting information

• Information about individuals stored is in registries

• Confidential information

• Eg: Hospitalisations & diagnoses, incarcerations

• Issue of privacy
## Creating linked data

1. **Professionals record patient data.**
2. **Patient data fed into standardised databases.**
3. **Demographic information extracted & sent to Data Linkage Unit (DLU).**
4. **DLU assigns demographic 'matches' the same linkage key.**
5. **Using links, DLU extracts de-identified data for an approved project.**
6. **Researcher receives population data.**
Databases available for linkage

**Family Connections**
- Births, Deaths & Marriages

**WA Health**
- Home & Community Care
- Aged Care Assessment Program
- WA Notifiable & Infectious Diseases
- Monitoring of Drugs of Dependence
- Drug & Alcohol Office
- State Trauma Registry
- WA Registry of Developmental Anomalies
- Health & Wellbeing Surveillance
- Reproductive Technology Register

**Core Datasets**
- Hospital Morbidity Data System (since 1970)
- Mental Health Information System (since 1966)
- Emergency Department Data Collection (since 2002)
- WA Cancer Registry (since 1982)
- Midwives Notifications (since 1980)
- Birth Registrations (since 1974)
- Death Registrations (since 1969)
- WA Electoral Roll (since 1988)

**WA Government**
- Dept of Child Protection
- Dept of Education
- Dept of Corrective Services
- Disability Services Commission
- Dept of Housing
- Dept of the Attorney General
- School Curriculum and Standards Authority
- Dept of Transport

**Other Organisations**
- Silver Chain Nursing Association
- Insurance Commission WA
- Main Roads WA
- St John Ambulance
- IDEA Database
- Breastscreen WA
- Playgroups WA
- Raine Study

**Geocoding**
- SEIFA & ARIA available for 1996, 2001 & 2006 censuses
Accessing data

Researchers need:
• Approval from Data Custodians
• Ethical approval separate committee

Restrictions include:
• No transferring or combining data-sets
• Data de-identified
• Only approved persons can access
• At least one WA investigator
• Data files password protected
Pre-existing maternal psychiatric disorders & child disability

Cases: mothers of children born from 1983-99 and later diagnosed with ID &/or autism

Comparisons: mothers of children born from 1983-99 with no ID or autism

Psychiatric measures: from details of all maternal public outpatient contacts (1969-1999)

**Intellectual Disability Exploring Answers (IDEA) database**

**Midwives Notification System database**

**Mental Health Information System**
<table>
<thead>
<tr>
<th>COB</th>
<th>Diag 1</th>
<th>Diag 2</th>
<th>Diag 3</th>
<th>D O B</th>
<th>Diag 4</th>
<th>Diag 5</th>
<th>Child diag</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mum 1</td>
<td>Aus</td>
<td>...</td>
<td>...</td>
<td>5/92</td>
<td>Psychiatric</td>
<td>...</td>
<td>...</td>
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<tr>
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<td>Aus</td>
<td>Gastro. Disorder</td>
<td>...</td>
<td>12/99</td>
<td>...</td>
<td>...</td>
<td>ID</td>
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<tr>
<td>Mum 3</td>
<td>NZ</td>
<td>Immune Disorder</td>
<td>Cancer</td>
<td>2/84</td>
<td>...</td>
<td>...</td>
<td>ASD</td>
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<tr>
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<td>Chad</td>
<td>Psychiatric</td>
<td>...</td>
<td>7/07</td>
<td>Cancer</td>
<td>...</td>
<td>...</td>
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<tr>
<td>Mum 5</td>
<td>UK</td>
<td>...</td>
<td>...</td>
<td>2/14</td>
<td>Organic Psychiatric</td>
<td>...</td>
<td>...</td>
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<tr>
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<td>Aus</td>
<td>Psychiatric</td>
<td>Self-harm</td>
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<td>...</td>
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<tr>
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<td>Aus</td>
<td>Immune Disorder</td>
<td>...</td>
<td>10/89</td>
<td>...</td>
<td>...</td>
<td>ASD</td>
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### Odds of a psychiatric disorder before the birth

<table>
<thead>
<tr>
<th>Maternal group</th>
<th>No. of mothers</th>
<th>Odds ratio</th>
<th>Confidence interval</th>
<th>Probability</th>
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<tbody>
<tr>
<td>No ID or autism</td>
<td>213,656</td>
<td>1</td>
<td>...</td>
<td>...</td>
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<tr>
<td>Any ID</td>
<td>4,866</td>
<td>2.07</td>
<td>(1.9, 2.3)</td>
<td>&lt; 0.0001</td>
</tr>
<tr>
<td>Any autism</td>
<td>1,043</td>
<td>2.11</td>
<td>(1.7, 2.6)</td>
<td>&lt; 0.0001</td>
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</table>
## Studies using linked data

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Limitations</th>
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<tbody>
<tr>
<td>• Large population cohorts</td>
<td>• Errors in matching</td>
</tr>
<tr>
<td>• Reliable measurement</td>
<td>• Privacy &amp; security need consistent vigilance (Sibthorpe et al., 1995)</td>
</tr>
<tr>
<td>• Retrospective data</td>
<td></td>
</tr>
<tr>
<td>• Relatively cheap</td>
<td></td>
</tr>
<tr>
<td>• Research in public interest</td>
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Acknowledgements & thank you

• University of WA
• Telethon Kids Institute
• Dr Helen Leonard
• Jenny Bourke
• Dr Nick de Klerk
• Data Linkage Unit of the WA Department of Health
Any questions?