Data Linkage in Tasmania: The Conception to Community Study

Data Linkage for Better Policy and Research
Hobart
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Conception to Community (C2C) Study

A long-term multi-disciplinary and cross-sectoral research program in maternal and child health and development in the Tasmanian community

- encompass integrated clinical and public health components
- reduce mental illness short- to long-term
- initial focus on perinatal and infant period
The C2C Public Services Database: Providing core data to address each piece in the puzzle
Objectives

– Establish baseline levels and trajectories of service utilisation and outcomes of mothers and infants (health, justice, developmental)

– Establish characteristics of mothers and children most at risk of high levels of service utilisation and poor outcomes

– Ascertain whole-of-community “disease burden” of “at risk” births

– Enable the impact and cost-effectiveness of future interventions to be assessed

– Illustrate to clinicians, policy-makers and the broader community the feasibility and potential of whole-of-state government data linkage within Tasmania (proof of concept)

– Translate the findings into clinical policy development and strategic planning initiatives.
The C2C Public Services Database

De-identified linked database of public sector Tasmanian datasets (Babies born 2008-09 to 2014-15) (H0014169)

Stage 1
- Perinatal (public);
- Emergency Department (public); and
- Admitted Patient (public).

<table>
<thead>
<tr>
<th>Mothers</th>
<th>Babies</th>
</tr>
</thead>
<tbody>
<tr>
<td>21,418</td>
<td>28,558</td>
</tr>
<tr>
<td>13,410</td>
<td>15,224</td>
</tr>
<tr>
<td>19,479</td>
<td>24,797</td>
</tr>
</tbody>
</table>

Stage 2
- Child Health and Parenting Service;
- Child and Adolescent MHS;
- Adult Community MHS;
- Drug and Alcohol Services;
- Mental Health Help Line;
- Child Protection;
- Juvenile Offender;
- Youth Justice.
Why use linked data?

– Routinely collected data, so no additional imposts on patients
– Large datasets – power
– Comprehensive data
  – At least whole-of-government perspective is feasible
  – Assess relationships and interactions, not feasible otherwise
– Longitudinal nature,
  – Can assess trajectories
  – Can assess impacts of interventions
Challenges encountered

– It took a little while ….. And then some.

<table>
<thead>
<tr>
<th>2014</th>
<th>2015</th>
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<tbody>
<tr>
<td>Apr May June</td>
<td>July Aug Sept</td>
</tr>
<tr>
<td>Scoping,</td>
<td>Data Linkage</td>
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<tr>
<td>Ethics Approval &amp; Data Release</td>
<td>&amp; Database Establishment for Approved Data</td>
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</tbody>
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First Tasmanian study using perinatal data – it takes time to establish Master Linkage Map

Ethics submitted June 2014
Ethics granted August 2014

Linkage keys sent November 2015
Datasets obtained January 2016

– Started getting collaborations established, but then couldn’t pursue
– Linking the mother and baby, there was a wild goose chase ….
– Make sure you are comprehensive in your data request.
– Cleaning: Duplicates/ Twins/ Missing data
  (17% baby, 13% mothers AP birth records).
Current status of the project

Stage 1
–  Perinatal inclusion of private hospital data so capture all Tasmanian births;
–  Emergency Department; and
–  Admitted Patient.

Stage 2
–  Child Health and Parenting Service;
–  Child and Adolescent MHS;
–  Adult Community MHS;
–  Drug and Alcohol Services;

What’s next?

Further collaborations
Expand Datasets included
Pursue funding opportunities
Project Team

CORE RESEARCH TEAM
Prof Fiona Judd
Assoc Prof Kristy Sanderson
Dr Fiona Wagg
Ms Angela Hay
Ms Kate Chappell (Data analyst)
Ms Eliza Nolan (Honours Student)

TDLU
Mr Brian Stokes
Ms Nadine Wiggins
Mr Tim Albion

Other Collaborators
Prof Alison Venn
Dr Anagha Jayakar
Ms Jane Austin
Ms Louise Newbery
Mr Simon Koop
Ms Jennifer Killworth
Why C2C?

Socio-economic factors are the major determinant of health and mental health outcomes in Australia

– Tasmania has the highest levels of socio-economic disadvantage among children in Australia

– Tasmania has the highest proportion of children at risk of social exclusions

Children of teenage mothers increased likelihood for behavioural problems and to live in social and economic disadvantage

– Tasmania has second highest level of teenage pregnancy

Mental health disorders are influenced by genetic and environmental interactions including stress

– Tasmania has the second highest level of diagnosed mental and behavioural problems in adults