Growing Up in New Zealand

The Data

With every external data release of the Growing Up in New Zealand data there are a few questions that are good to understand and know the answers to. Read on to find out:

- How the background of the study influences the policies to keep the data anonymous and prepare for external researchers to access the data.
- More about the debate surrounding the data release.
Growing Up in New Zealand is a longitudinal study that provides an up-to-date, population relevant picture of what it is like to be a child Growing Up in New Zealand in the 21st century. Approximately 7,000 children and their families are taking part in a study that aims to provide a complete picture of the pathways that lead to successful and equitable child development, therefore improving outcomes for all children - now and into the future.

Growing Up in New Zealand is explicitly designed to follow children from before birth until they are young adults to understand “what works” for children and families and to consider pathways of development across multiple domains of influence. This will allow the much better understanding of the complex interplay of all the factors that lead to child outcomes including growth, health, behaviours and cognitive development, in the context of the child being in dynamic interaction with their families, communities, environments and societal contexts over time.

Background
Growing Up in New Zealand is a longitudinal study that was set up in response to a recognised need by New Zealand policymakers for robust, contemporary, population relevant evidence to inform their efforts to improve the quality of New Zealanders’ lives. The Growing Up in New Zealand data is a valuable resource and it provides a real platform for:

- Researchers to gain a better understanding of the causal pathways that lead to particular developmental outcomes
- Policy makers to inform strategies to optimise development
- The children and families who take part in this study as well as for all future generations of New Zealanders

Keeping the study data anonymous

One of the most important ingredients of the Growing Up in New Zealand study is keeping the participant data anonymous. This not only protects the privacy of every participant but enables us to ask questions about lifestyle, health and social issues that might not be so freely accessible if not kept so confidential. Therefore, the Study must manage the balance of keeping the participant data anonymous whilst also providing data that can be used to drive robust, contemporary, population relevant evidence.

To manage this balance, access to the Growing Up data is driven by the requirements set out in the Growing Up in New Zealand Data Access Protocol (initially established in 2008) and overseen by the Data Access Committee. The requirements of this protocol have therefore driven the approach taken to release any dataset externally. This covers the release of a fully anonymised dataset along with processes to ensure that participant anonymity is protected whilst also allowing the data to be used effectively and widely.
Releasing the data – the debate

How to release the *Growing Up in New Zealand* data has been a subject that has evoked considerable debate. This type of data release, where an anonymised dataset is made publically available, is an uncommon approach in New Zealand and as such there are few examples to model the release on. However, this approach is common for longitudinal studies overseas and is widely accepted and embraced by the international research community. Therefore, in New Zealand this Study is leading the way in publically releasing an anonymised dataset. However, in world terms, we are following standard approaches and processes.

It is envisaged that it will take time for the processes and approach to become embedded in the New Zealand research community and we welcome further debate on this approach.

How the data can be accessed

The model used for other international longitudinal studies is that there are two types of research datasets. This same model is used by *Growing Up in New Zealand* where there are two types of *Growing Up in New Zealand* datasets:

- **The External Working Dataset** is the publically available anonymised dataset. Researchers wishing to access the External Working Dataset should apply to the National Institute for Health Innovation (NIHI) who *Growing Up in New Zealand* has partnered with to manage the release of the *Growing Up in New Zealand* data.

- **The Internal Working Dataset** is a more detailed dataset which requires much greater control and security. Access to the Internal Working Dataset requires appointment to the *Growing Up in New Zealand* Research Team. Researchers wishing to discuss collaborations and work with the Research Team should contact Associate Professor Susan Morton, Director, *Growing Up in New Zealand*.

See this link for full details: [http://www.growingup.co.nz/data-workshops.shtml](http://www.growingup.co.nz/data-workshops.shtml)

### Definitions of the datasets

The *Growing Up in New Zealand* datasets are defined in the *Growing Up in New Zealand* Data Access Protocol.

- **The Internal Working Dataset** is a more detailed dataset which requires much greater control and security. Access to the Internal Working Dataset requires appointment to the *Growing Up in New Zealand* Research Team. Researchers wishing to discuss collaborations and work with the Research Team should contact Associate Professor Susan Morton, Director, *Growing Up in New Zealand*.

- **The External Working Dataset** means a fully anonymised dataset drawn from the Internal Working Dataset. All Approved Researchers outside the *Growing Up in New Zealand* Research Team will work with data of this kind. External Working Datasets will not contain any Identifying Information.

### Data Collection Waves

Each Data collection Wave (DCW) of *Growing Up in New Zealand* seeks information across six inter-connected domains: family and whānau (extended family), societal context and neighbourhood, education, health and wellbeing, psychological and cognitive development, and culture and identity.

<table>
<thead>
<tr>
<th>Child age</th>
<th>Antenatal</th>
<th>Perinatal</th>
<th>6wks</th>
<th>35wks</th>
<th>9mths</th>
<th>12mths</th>
<th>16mths</th>
<th>23mths</th>
<th>2yrs</th>
<th>31mths</th>
<th>45mths</th>
<th>54mths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother CAPI*</td>
<td>•</td>
<td>•</td>
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<tr>
<td>Partner CAPI*</td>
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<tr>
<td>Mother CATI†</td>
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<td>Child‡</td>
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<tr>
<td>Data linkage**</td>
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</tr>
</tbody>
</table>

* CAPI computer assisted personal interview
† CATI computer assisted telephone interview
‡ Child measurement
** Linkage to health records (eg National Minimum Dataset, National Immunisation Register)

Internal Working Datasets are defined in the Data Access Protocol as:

‘Internal Working Dataset means the primary dataset after the necessary restructuring and cleaning of the raw data collected from Study Participants. This will be a repository for information that accumulates with each wave, together with derived variables and linked data. It will have Identifying Information removed (but will not be fully anonymised) and will only be linkable to data that may lead to identification over time via an identity number. This dataset will be subject to appropriate security measures. The *Growing Up in New Zealand* Research Team will at times use the Internal Working Dataset.’

Table 1 - Summary of Data Collection Waves (DCW)
inter-connected domains, in the context of the overarching longitudinal research objectives, while being as policy relevant as possible. Attention is also given to ensuring that the methods utilised to collect domain-specific evidence acknowledges the unique New Zealand population and environmental context.

Table 1 summarises the data collection waves that will have been undertaken (by end 2014).

### The first external data release

The first dataset being released externally by the Growing Up in New Zealand Study is the Antenatal Dataset. This provides the data from face to face interviews that were undertaken with approximately 7,000 Mothers who were due to have their babies between 25 April 2009 and 25 March 2010. The data covers the antenatal period.

Included, is the information from the Mothers current partners, which was also gathered via face to face interview.

Therefore, there are two datasets that are being released at this time:

- **Antenatal Mother**
  - External Working Dataset
- **Antenatal Partner**
  - External Working Dataset

### Status of the datasets

The table below summarises the status of each *Growing Up in New Zealand* dataset noting for each DCW the status of the External Working Dataset and the Internal Working Dataset.

<table>
<thead>
<tr>
<th>Data Collection Wave</th>
<th>External Working Dataset</th>
<th>Internal Working Dataset</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antenatal</td>
<td>Applications welcomed from June 2013</td>
<td>Available to the Growing Up in New Zealand Research Team</td>
</tr>
<tr>
<td>Perinatal</td>
<td>Fully anonymised dataset being prepared</td>
<td>Available to the Growing Up in New Zealand Research Team from May 2013</td>
</tr>
<tr>
<td>6 Weeks</td>
<td>Raw data being restructured and cleaned</td>
<td>To be confirmed</td>
</tr>
<tr>
<td>9 Months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 Months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16 Months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23 Months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Two Years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31 Months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>45 Months</td>
<td>Data collection in the field (to March 2014)</td>
<td></td>
</tr>
<tr>
<td>53/54 Months (Pre School)</td>
<td>Data collection in the field (May 2013 to December 2014)</td>
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### Further information

For more details on this technical summary of the *Growing Up in New Zealand* data or any other part of this study please visit our website and contact us.

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**Glossary**

- **Data Access Protocol**
  - The Data Access Protocol is a key document that sets out how the data from Growing Up in New Zealand can be used. All Researchers applying to use Growing Up in New Zealand data must be familiar with the Data Access Protocol.

- **Data Access Committee (DAC)**
  - The purpose of the Data Access Committee is to facilitate the provision of appropriate access to data collected in the Study by Approved Researchers under the terms and conditions of the Data Access Protocol. As such, External and Internal Working Datasets can not be used without the prior approval of DAC.