



Waipapa
Taumata Rau
University
of Auckland

Growing Up
in New Zealand

17 Year Data Collection Wave

Primary Caregiver
Participant Information Sheet

Leading Light: Te Rōpū Pīata

We would like to invite you to continue being part of the *Growing Up in New Zealand* study, hosted by the University of Auckland.

When you first signed up to be part of *Growing Up in New Zealand* you did so believing that the study was important. Now that that your child/children in the study is/are 16-years old it is important that we give you to opportunity to decide if you would like to remain part of *Growing Up in New Zealand*.

What is Growing Up in New Zealand?

Growing Up in New Zealand has been following the lives of more than 6,000 young people since they were born in 2009/10 so that we can understand what it is like to be a child in New Zealand. Studies like ours are unique, helping to understand how the things that happen during childhood influence and shape what our lives might be like as adults.

Growing Up in New Zealand is different from other research projects being done in New Zealand at the moment.

- It is a population study, which means it does not look at just one area of a child's life like health or education.
- It asks questions about a wide range of areas including your family/whānau, your neighbourhood, health and wellbeing, education, development and living in New Zealand.

- We follow the same group of people over time – if a participant/family decides to leave the study they cannot be replaced.

We ask these questions so we can understand all the different types of families in New Zealand and the families of the children in *Growing Up in New Zealand*.

The information learnt from this study has already been used to improve the lives of New Zealand children, and it will continue to do so into the future.

What have we done so far?

The *Growing Up in New Zealand* study has been collecting a really wide range of information about you, your child, and your household from when you were first in the study.

Information about you and your household



Demographics

Your age at the antenatal interview, ethnicity, country of birth/year of arrival to NZ, gender



Housing and neighbourhood

Home ownership, rentals, housing condition, cost of housing, neighbourhood, number of times you have moved, homelessness



Employment and Income

Highest educational qualification, employment status and type of work, maternity leave, personal income, household income, debt, loans, savings, benefit use, Working for Family's Tax Benefit, transport



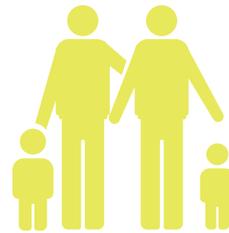
Physical and mental health

General health, disability, fertility, planned/unplanned pregnancies, height/weight in pregnancy, diet, physical activity, health diagnoses, smoking, alcohol, drug use, depression, anxiety



Access to healthcare

Antenatal classes, Lead Maternity Carer, GP enrolment and use, hospitalisations, health insurance/cost of healthcare



Household Relationships

Number of people in your family/whānau and household and their ages, spousal or partnered relationships, interparental conflict, verbal and physical violence, parenting approach, parenting stress, parent-child relationship, use of discipline

Information about your study child(ren)



Demographics

Their ethnicity, sex at birth



Housing and neighbourhood

The number of times and reasons you moved house, connections to your neighbourhood and community groups, access to the internet



Use of health services and other government agencies

GP, immunisations, other health checks



Culture and identity

Their sense of belonging to NZ, discrimination, cultural affiliations, languages spoken at home and other places, involvement in sports, cultural groups, music groups, and other activities



Emotional and social development

Infant/toddler activities, language development, feelings towards themselves, their reactions in different situations, behaviour, developmental concerns, peer relationships, bullying, screen use



Health and wellbeing

Their birth information, any illnesses, health problems or concerns, body image, puberty, mental health, self-harm



Relationships with family and friends

Number of people in your family/whānau and household at each stage of your life, changes to your family including your parents relationship, conflict in the home



Sleep, activity and diet

Their diet at different stages of life, family food behaviours, quality and quantity of sleep, how active they are

We have also asked for permission to access information collected about you and your child by government departments and other health and social service providers. Accessing this information helps to reduce the number of questions we need to ask you and how long you spend completing your questionnaires.

What is involved?

If you agree to continue being part of this study, we will invite you to complete a questionnaire or to take part in a research activity (e.g. interviews). This will happen every 2 to 4 years. We might also contact you to help us understand how sudden, national events (e.g. extreme weather events) impact on your health and wellbeing.

You do not have to complete all of the questionnaires or interviews that we invite you to complete. You can choose to skip a questionnaire if you want to without giving any reason – that is ok.

We will also send you updates on the study and to check to see if you have moved. Keeping in touch means we know how to contact you when the next questionnaire is ready.

What about data linkage?

Data linkage is a process used by researchers and policy makers to join different bits of information collected about individuals from a range of different surveys, research studies, and government databases. Data linkage helps to reduce the number of questions we need to ask you, which means you can spend less time completing the questionnaire.

We would like to ask your permission to do two different types of data linkage:

Data linkage at the University of Auckland:

- We will ask your permission to access data that has already been collected about you by government agencies (e.g. the Ministry of Education, the Ministry of Health).
- If you agree, then those agencies will share a copy of your data with the Growing Up in New Zealand study at the University of Auckland, where we

will be responsible for storing it, protecting it and looking after it.

- Researchers who wish to access the linked (or joined up) dataset will apply to the Growing Up in New Zealand study and our Data Access Committee who will be responsible for making sure that the researchers meet our strict protocols for keeping you and your data safe.

Data linkage at Statistics New Zealand:

- We will ask your permission to share a copy of some of your 17 Year Data Collection Wave information with Statistics New Zealand (“Stats NZ”) so that it can be joined with other information collected about you by the Government and analysed in the Integrated Data Infrastructure (IDI). You can find out more about Stats NZ and the IDI on our website.
- If you agree, then the Growing Up in New Zealand study will share a copy of your 17 Year Data Collection Wave information with Stats NZ, where

they will be responsible for storing it, protecting it and looking after it.

- Researchers who wish to access the linked (or joined up) dataset will apply to Stats NZ, and they will be responsible for making sure that the researchers meet our strict protocols for keeping you and your data safe.
- Stats NZ can recommend that researchers contact specialists from the Growing Up in New Zealand team at the University of Auckland to ensure that the research will help children and young people in New Zealand. However, the Growing Up in New Zealand team will not make any decisions about which researchers can access your data and which projects are approved. Stats NZ will be responsible for making those decisions.

Both types of data linkage are optional – you can choose to do both, one, or none – whatever you decide is ok. You can still take part in the 17 Year Data Collection Wave, no matter what.



What happens to my Growing Up data? Who will be responsible for keeping my Growing Up data safe?

If you agree to stay involved, then your existing data and any new data we collect from you in the future will be stored kept safely and securely under the guardianship of the *Growing Up in New Zealand* study. Right now, our data system is hosted in Sydney, Australia, within a secure data centre.

The University of Auckland and the *Growing Up in New Zealand* team are responsible for storing your data, protecting it, and looking after it. We are also responsible for ensuring that any research that uses *Growing Up in New Zealand* data is in the best interests of the public and that approved researchers use the data safely.



Researchers are able to apply to access a copy of the full data by applying to the *Growing Up in New Zealand* study. These applications are assessed by the *Growing Up in New Zealand* Data Access Committee, which has strict criteria that researchers must meet to access data. You can find out more about these criteria on our website.

Researchers from overseas are able to apply to access the *Growing Up in New Zealand* dataset, however, they must have a New Zealand-based researcher on their team.

You can find some examples of research projects that have used the *Growing Up in New Zealand* data on our website.

What are the benefits of being part of the *Growing Up in New Zealand* study?

The information you provide to the study will potentially benefit children and young people because your answers will help the government and other agencies to make policies that improve the lives of all New Zealand children.

You will be offered a small gift after completing a questionnaire or interview as a way of thanking you for your time and generosity. There is no direct compensation for being involved.

What are the risks?

The *Growing Up in New Zealand* study has worked hard over the years to identify and reduce any possible risks involved with the study. However, whenever you take part in any study there are some

risks, including the following.

- Feeling upset by the questions we ask due to their personal or sensitive nature.
- The possibility for individuals, and maybe others who live in the same household, organisation, iwi or hapū, to be re-identified in the data. This means someone might be able to piece together a collection of data and figure out that they are about you.
- The possibility of a data security failure, i.e. someone hacks into the University of Auckland data system.
- The possibility data is used for non-approved purposes, i.e. data is shared with someone/group who is not an approved researcher.
- A researcher may come up with answers that make some people and/or communities feel upset because they don't reflect what matters most for them.

Growing Up in New Zealand has a plan for each of these risks and works hard to ensure they do not occur. More information about what we do to keep your data safe can be found on our website.

How should I decide what to do?

The first thing to know is that there is no right or wrong way to make a decision about staying involved in the *Growing Up in New Zealand* study.

Take the time to make sure you have all the information and advice that you need to make the decision to continue being part of the study.

It is important that you have the opportunity to make your own decision about what you would like to do. Your child has consented to stay involved in the study. We know you have provided a lot of information about

yourself, your child, and your household which is able to be used to answer important research questions. Because of this, you might feel strongly about staying involved in the study. You will continue to provide information about yourself, your household, and your child. We will not ask your child to provide information directly about you.

What happens if I want to stay involved?

We will invite you to take part in the next questionnaire or interview. This means you can choose to take part, or not, knowing that your child has consented to stay involved in the study.

If you agree to stay involved but later change your mind, that is ok. You can contact the *Growing Up in New Zealand* team at any time and we will help you.

What if I want to leave the study?

You can say no to this request if you want to. That is ok. We appreciate all of the time and information that you have already given to the *Growing Up in New Zealand* study.

If you say no then we will remove your contact information from our database and you will no longer be invited to take part in our questionnaires/interviews.

Your child will remain part of the study as they have consented. We will continue to ask them questions about their own health and wellbeing and about your household. They will not be asked to share any information about you.

If you say no then we will ask your permission to keep the information you have already provided at the University of Auckland so that researchers can continue to answer important questions about what it takes to ensure all children are able to live a good life in New Zealand.

- If you agree, the University of Auckland and the *Growing Up in New Zealand* study will continue to take care of it and make decisions about how it is used for research and policy.
- If you disagree, then a member of the *Growing Up in New Zealand* team will safely remove your individual data so that it is no longer available for researchers to use in their new projects. It may take up to 6 months for this process to be completed. However, your data cannot be removed from projects that are already underway or have been completed.

We will also ask you for your permission to continue storing any biological samples that have been shared with the *Growing Up in New Zealand* study.

- If you agree, the University of Auckland and the *Growing Up in New Zealand* study will continue to take care of it and make decisions about how it is used for research and policy.
- If you disagree, then a member of the *Growing Up in New Zealand* team will safely dispose of the sample(s) and data so that it is no longer available for researchers to use in their new projects. It may take up to 6 months for this process to be completed. If your sample has already been processed then there may no longer be any left for the study to store and dispose of. Your biological data cannot be removed from projects that are already underway or have been completed.



Who is funding the study?

The study is based at the University of Auckland and funded by the New Zealand government via a contract with the Ministry of Social Development.

This study has been approved by an independent group of people called a Health and Disability Ethics Committee (HDEC), who check that studies meet established ethical standards. The Northern B committee has approved this study (Ref NTY/08/06/055).

Any more questions?

We are happy to answer any questions you may have about this proposal to change the storage of your *Growing Up in New Zealand* data. Here are some of the places you can go for help with any questions:

Email: contact@growingup.co.nz or

Phone: **0508 GROWING UP (0508 476 946)**

More information about the study is available at growingup.co.nz.

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: **0800 555 050**
Fax: **0800 2 SUPPORT (0800 2787 7678)**
Email: advocacy@advocacy.org.nz

Website: advocacy.org.nz/

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Email: hdecs@health.govt.nz
Phone: **0800 400 569**
(Ministry of Health general enquiries)

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Statement of Approval:

This study has received ethical approval from the Health and Disability Ethics Committee (Ref NTY/08/06/055). Ethical approval means that experts who are not involved with *Growing Up in New Zealand* have checked all of our information and activities, and are happy that there is nothing that would be harmful for you or your family, that information will be kept private, that this study will be helpful for New Zealand families.

Formal Study title: *Growing Up in New Zealand*
Sponsor: Ministry of Social Development
Research Director: Professor Sarah-Jane Paine
Study Site: The University of Auckland, Private Bag 92019, Auckland 1142, New Zealand
Ethics committee ref.: NTY/08/06/055/AM0434



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The logo for 'Growing Up in New Zealand', consisting of a stylized 'G' and 'U' icon followed by the text 'Growing Up in New Zealand'.