



Waipapa
Taumata Rau
University
of Auckland

 **Growing Up**
in New Zealand

Young Person Re-consent Participant Information Sheet

Leading Light: Te Rōpū Pīata

17 Year Data Collection Wave

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 your mother first signed up to be part of *Growing Up in New Zealand*, she did so believing that the study was important and that you would have made the same choice if you had been able to. Now that the children in the study are 16 years old, it is important that we give you the 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.



Demographics

Your ethnicity, sex at birth

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 mother/primary caregiver and your household since before you were born.

In the early years of your life, your mother/primary caregiver was the person who provided your information to us, but since the 8-year data collection wave, you have also had the chance to tell us what life is like for you growing up in New Zealand.



Housing and neighbourhood

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



Health and wellbeing

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



Emotional and social development

The types of activities you did as a baby/toddler, language development, how you feel about yourself, your reactions in different situations, behaviour, developmental concerns, peer relationships, bullying, screen use



Culture and identity

Your 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



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

Your diet at different stages of your life, family food behaviours, quality and quantity of sleep, how active you are

Other types of information that you or your primary caregiver has shared with the study include:

- Biological samples (including things such as Guthrie newborn metabolic screening, saliva samples, skin/nose/throat swabs)
- Audio recordings of you interacting with your primary caregiver
- Observations of you completing games/tasks as a young child
- Open-ended questions in the surveys (such as: what are your hopes for your child's future?)
- Information about your schooling collected from your teacher

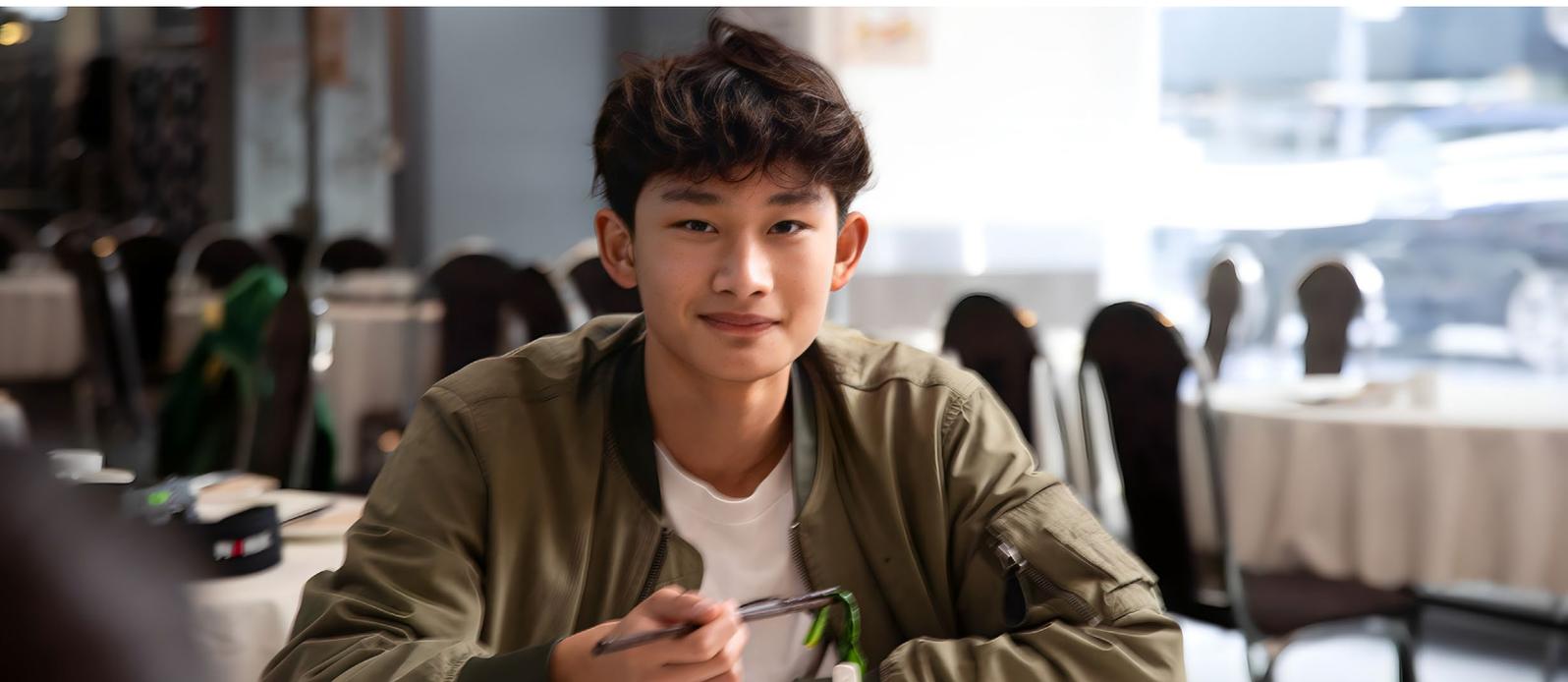
We have also asked for permission to access information collected about you by government departments and other health and social service providers. Accessing this information helps to reduce the number of questions we need to ask you and how long you spend completing your questionnaires.

What is involved?

If you agree to continue being part of this study, we will ask you to provide us with your contact details so that we can invite you to complete a questionnaire or to take part in a research activity (e.g. physical health assessments, 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 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 use these contact details to send you updates on the study and to see if you have moved. Keeping in touch means we know how to contact you when the next questionnaire is ready.



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 of data being used for non-approved purposes, i.e. data is shared with someone/a 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 to 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.

You might like to ask your mother/primary caregiver why they thought being part of *Growing Up in New Zealand* was a good idea and if they still feel the same way. You might also like to talk to other members of your family/whānau – that is ok too. Take the time to make sure you have all the information and advice that you need.

It is important that you have the opportunity to make your own decision about what you would like to do. However, we also know that being part of the study has been a family/whānau choice and that your mother/primary caregiver has played a very important role in the study, providing information about you when you were too young to do that yourself and helping you complete your own questionnaires. They have also provided a lot of information about themselves and your household, which is able to be used to answer important research questions. Because of this, they might feel strongly about staying involved in the study. For this reason, your mother/primary caregiver is being offered the chance to stay involved in the study even if you choose not to. However, they will only be able to provide information about themselves or your household. We will not ask them to provide information directly about you.

What happens if I want to stay involved?

We will update the contact details in our system so that we can invite you to take part in the next questionnaire or interview. This means you can choose to take part, or not, without having to check with your mother/primary caregiver as you have done up to now.

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 mother/primary caregiver will remain part of the study if that is what they want to do. However, we will only 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 your data 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 your biological sample(s) 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.

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.

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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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