



Growing Up in New Zealand

**15 YEAR  
CATCH-UP**

**Mother/Primary caregiver  
participant information sheet**





***Growing Up in New Zealand*** would like to thank you and your family for giving so much of your time to the study over the past 15 years. The information you generously share is helping to make Aotearoa New Zealand a better place for young people.

You are invited to take part in the next phase of the *Growing Up in New Zealand* study: The 15 Year Catch-Up.

Please take your time to read through this information sheet, which has been developed to help you decide if you would like to take part.

This information sheet explains:

- Why we are doing the study.
- What your participation involves.
- The potential benefits and any risks of being involved.
- What happens to the information you share with us.

We are here to help, so please get in contact with us if you have any questions.

You can contact the interviewer you spoke with during your pre-interview/ scheduling call who can go through this information with you and answer any further questions you may have.

You can also call our helpline or text messaging service between 9am and 9pm, seven days a week: 0508 GROWING UP (0508 476 946). Or email us at [contact@growingup.co.nz](mailto:contact@growingup.co.nz) anytime.

Ngā mihi nui.

## **What do I need to know about the 15 Year Catch-Up questionnaires?**

You can choose to do the questionnaire online, online with the support of an interviewer on the phone, or in person. It will take about 30 minutes for you and your young person/people to complete each questionnaire.

If you do not have a suitable device available to complete the online questionnaires, then we can help.

We can arrange for a loan device to be delivered to you so you can take part in the 15 Year Catch-Up. This device would have its own mobile data so would not use your household data. Please let us know if you require this assistance.



# What is the purpose and design of the study?

## The purpose of the study

Thousands of young people and their families, including you and your whānau, are at the heart of *Growing Up in New Zealand*.

*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 person's life like health or education. It will ask questions about your family or whānau, your neighbourhood, health and wellbeing, education, your job, your young person's development, and living in New Zealand.

We ask these questions so we can understand all the different types of families of the young people in *Growing Up in New Zealand*. The information learned from this study will be used to improve the lives of all New Zealand young people.

This University of Auckland study is this country's largest longitudinal study of youth development. It has been following the lives of more than 6,000 young people since 2009 and 2010, when their mothers were pregnant.

The young people in the study reflect the ethnic and socioeconomic make-up of Aotearoa New Zealand today. This helps to provide accurate information about what works to support all young people to have happy, healthy, and fulfilling lives.

The information the study gathers provides valuable insights for decision-makers to make real changes to improve the lives of all young people in Aotearoa New Zealand.

The *Growing Up in New Zealand* study has contributed to a range of policy developments including:

- Paid parental leave.
- Immunisation.
- Preventing childhood injuries.
- Understanding of poverty and material hardship.
- Housing.
- Early childhood education.
- NZ infant feeding guidelines.

The *Growing Up in New Zealand* study is considered a taonga, or a treasure. The wealth of information we collect about young people and their families grows in value over time because it increases our understanding about how different factors early in life influence outcomes for young people as they grow into adulthood.



## The design of the study

*Growing Up in New Zealand* was designed as longitudinal from the outset with an explicit intent to both relate to the current policy context and inform future policy development. The four overarching objectives are to:

- Map the developmental trajectories for a cohort of New Zealand children, in order to identify the main causal pathways, and the links between them, across multiple levels of influence (political, social, cultural, intergenerational, familial and individual) for outcomes in key social, developmental and health domains across the lifecourse;
- Describe outcomes at key points in the lifecourse of the developing child to enable comparisons between subgroups and within subgroups (including by ethnic identity), and with international populations;
- Focus on factors and trajectories that confer resilience and optimise development, rather than focusing solely on risk factors for poor outcomes and;
- Identify critical periods in development, and areas of influence, that will allow the development of policy directed at optimising the lifecourse development of every child born in New Zealand.

We visit or check in with the study participants and their families around every two to four years to gather vital information so that we can build a picture of what it's like to be a young person growing up in the complex world of 21st Century Aotearoa New Zealand.

These interviews often consist of a combination of activities, including questionnaires, physical measurements, the collection of samples, and other tasks.

Study participants can also be asked to give permission for *Growing Up in New Zealand* to link to routinely collected Government data like information on health and education. This helps researchers to develop an even more detailed picture of young people's development.

We plan to continue to connect with the study young people until they are at least 21 years old.

If the study ends when your child becomes an adult, the information will be kept until the youngest child in the study reaches maturity plus 10 years (26 years old).



## What will my participation in the 15 Year Catch-Up involve?

You have received this information sheet because you initially agreed to be part of *Growing Up in New Zealand* study and the 15 Year Catch-Up when we contacted you to discuss how you might like to complete this data collection.

If you have asked for a face-to-face interview, our interviewer will ask you to complete an online consent form and we can guide you through this process. If you have decided to use telephone assistance during the 15 Year Catch-Up, then the interviewer can also guide you through the consent process. If you selected to do the 15 Year Catch-Up

electronically with no assistance the consent forms will be at the start of your questionnaire. If you have any questions, please contact us.

You can find more details about what you'll be asked to provide consent for later in this information sheet.

Remember, you can consent to all, some, or none of the questionnaires that make up the 15 Year Catch-Up. If you choose to only take part in some of the questionnaires that is okay, and you will still be part of the study.





## What is included in the 15 Year Catch-Up?

This Catch-Up involves collecting information from young people in the study, and their primary caregiver, when they are around the age of 15-years.

We've chosen to touch base with your young person again at this age because it is a critical time in young people's development – just after they have become teenagers. We want to learn more about what's important to them, what they like to do, and how they view their place in the world.

### There are two different parts to the 15 Year Catch-Up:

1. A questionnaire for you as the mother or primary caregiver to answer questions about your young person/people and about your family.
2. A questionnaire for your young person/people about their lives.

### Below you can learn more about the different parts of the 15 Year Catch-Up questionnaires:

**Your young person/people's questionnaire** will take about 30 minutes to complete. We will send you a link to the questionnaire during our call with you and your young person.

A *Growing Up in New Zealand* interviewer will be available by telephone or in person (if a home visit has been requested) to support you and/or your young person to complete their questionnaire and answer any questions they may have.

### The questionnaire asks about:

- The young people's health - how they are and how they feel about their life.
- What they think about school.
- Puberty.
- Self-harm and suicide.
- Who they are and what they think about living in Aotearoa New Zealand.
- Ethnic identity and cultural connectedness. Their family life and relationships.
- Their everyday life.

**The mother's/primary caregiver's online questionnaire** will take about 30 minutes. You will receive a link to this questionnaire by email.

### The questions will ask about:

- Access to and use of government services for your young person/people.
- Health and disability of your young person/people.
- Your employment, income, and housing.
- Hopes for your young person/people's future.

# Do I have to take part in the 15 Year Catch-Up?

It is your choice whether to take part in all, or any, of the 15 Year Catch-Up.

If you do not want to take part, you don't have to give a reason and it won't affect your involvement with the rest of the *Growing Up in New Zealand* study. If you want to take part now, but change your mind later, you can pull out at any time.

You may want to talk about the 15 Year Catch-Up and your involvement with the study with other people, such as family, whānau, friends, or your healthcare provider before you decide about whether to participate.

## What are the possible risks of taking part in this study?

The information that you share with us will always be treated with the utmost respect, privacy, and care. We have strict controls in place to restrict who has access to the data and will continue to protect your information and data. However, whenever you take part in any study there are some risks, which we outline below.

### Risks that you or your young person may be upset by the questionnaire

Some of the questions we ask are personal or concern areas of development that may make you or your young person feel uncomfortable or possibly upset. If this is the case, please contact someone to talk about this further. A list of contacts is provided at the end of this information sheet which may be helpful, or you can phone the study team on 0508 GROWING UP (0508 476 946) or discuss this with a family member or friend.

### Privacy risks

*Growing Up in New Zealand* makes every effort to protect your privacy, but absolute confidentiality of your information cannot be guaranteed, even with de-identified information. However, the risk of people accessing and misusing your information is very small. This risk may increase in the future with new ways of using information.

### Data analysis risks associated with research of international interest

All research projects are assessed by the *Growing Up in New Zealand* Data Access Committee, which has strict criteria researchers must meet to access data. The *Growing Up in New Zealand* data is accessed and analysed using a secure cloud-based system which prevents researchers from being able to download or remove your data during their projects.

The *Growing Up in New Zealand* secure system is hosted in Sydney, Australia, within a secure data center and network architecture. This infrastructure has been designed to align with 143 security standards and compliance certifications, meeting global security requirements, to keep your de-identified data safe.

Researchers from New Zealand and overseas can request access to the *Growing Up in New Zealand* datasets, and there is no guarantee a New Zealand-based researcher will be represented on an overseas research project. This means there is a risk that overseas researchers may represent information in a way that does not align with how we think about wellbeing in New Zealand, including for Māori, Pacific, and Asian families in our study.

Existing DNA samples (from saliva) collected at four and eight-years of age may be sent overseas (if you consented) for analysis. There may not be New Zealand representation on their governance committees. Skin microbiome swabs are not currently sent overseas.

### Linking to other datasets

Linking *Growing Up in New Zealand* data to other routine data collected by the government, such as health and education data (see information on data linking below) can help to produce a more detailed picture of individuals.

However, linking data in this way also increases the risk individuals could be identified. This could include others who may be in the same household, organisation, iwi or hapū. Some of this routinely collected health or education data may have been collected in ways which have resulted in biases. This means there is the potential for inappropriate conclusions to be drawn. We have taken steps to minimise the likelihood of this happening, but we cannot guarantee they will not occur.

See more about linking study data in the section "How do we add additional information to the study?"

### Risk of reinforcing stereotypes

*Growing Up in New Zealand* research includes basic information such as you and your young person's ethnic group, geographic region, age range, and sex. It is possible that this research could one day help people in the same groups as you. However, it is also possible that research findings could be used inappropriately to support negative stereotypes.

# What are the possible benefits of taking part in the study?

The information you provide to *Growing Up in New Zealand* helps researchers to learn more about what supports young people in Aotearoa New Zealand to have a good life. It means they can learn more about:

- Health and wellbeing
- Education
- How services and government assistance can best support young people.
- Neighbourhoods and society

This information will help current and future researchers, along with the government and other agencies to make changes to improve the lives of all young people in Aotearoa New Zealand.

*Growing Up in New Zealand* research is world-leading, and you are part of something very special which can make a difference for all New Zealand families. As this is a longitudinal study, the information collected becomes more valuable over time as it helps researchers understand how different factors can affect young people's growth, development, and wellbeing throughout their lives.

By being part of this study, you are contributing to a greater public good which will hopefully benefit many future young people in Aotearoa New Zealand.

We will give you and your young person/people a small gift as koha or thanks for their involvement in the study. However, there is no direct compensation for participating.

# What will happen to my information?

During the 15 Year Catch-Up, the *Growing Up in New Zealand* team will collect information about you and your young person/people.

Depending on what you consent to, this could include information from you and your young person/people's questionnaires.

This will be added to the information *Growing Up in New Zealand* has collected from you and your young person/people over the life of the study.

We ensure that any information that could directly identify you or your young person/people is kept separate from the information you give us during interviews.

Generally, we do not give your young person/people's individual results back to you, as we are not looking at any of the information at the level of an individual person.

Below, you'll find a summary of the type of information we hold about you and your young person/people, along with details about how we keep it safe.

## Identifiable information

Identifiable information is any data that could identify you such as your name, date of birth, or address.

Only authorised members of the *Growing Up in New Zealand* team have access to your identifiable information, so they can stay in touch with your family. No one else has access to this information, including any data users. Similarly, no one who has access to your identity information has access to your research information. The two are kept separate.

## De-identified or coded information

All study data is de-identified, which means anything that can identify you (such as your name or address) is removed.

Your de-identified data is recorded using a specific code assigned to you at the beginning of the study.

No information that could identify you or your young person/people will be included in any report generated by *Growing Up in New Zealand* or any other research.

## Security and storage of your information

The safe and secure storage of your data is a priority for *Growing Up in New Zealand*.

As *Growing Up in New Zealand* is a longitudinal study the de-identified data collected from you and your young person/people will be stored at the University of Auckland for at least 10 years after they turn 16 years of age so that it can be accessed by approved researchers in the future.

The University of Auckland and the *Growing Up in New Zealand* Data Access Committee are responsible for its safekeeping.

Any study data provided by third parties, such as those processing biological samples, is transferred using the University of Auckland's strict data transfer protocols. The biological samples will be kept at least until the young people reach 16, plus 10 years (26 years).

Any identifiable information collected about you is securely held at the University of Auckland and there are strict protocols around who can access this. This information will be kept until the study ends or when the young person/people are 26 years (whichever comes later).



## Access to Growing Up in New Zealand data

All researchers who wish to use the de-identified data must comply with the *Growing Up in New Zealand* Data Access Protocol.

This protocol exists to protect your privacy and ensures that data are used according to the overarching aims of the study which you agreed to when you consented to take part in the study.

The following groups may have access to your de-identified information once their projects have been approved by our Data Access Committee:

- Researchers within the University of Auckland.
- Researchers outside of the University of Auckland and/ or outside of New Zealand who work for an accredited research organisation. These researchers access the data via a secure digital platform based at the University of Auckland.

The results of a study that uses your *Growing Up in New Zealand* data may be published or presented, but not in a form that would identify you.

## How Growing Up in New Zealand practices Kaitiakitanga

*Growing Up in New Zealand* is founded on principles that focus on equity, te Tiriti o Waitangi (the Treaty of Waitangi) and Kaitiakitanga (guardianship). These principles guide the appropriate and safe collection, storage, analysis and use of Māori data and knowledge.

All data access applications are reviewed according to the *Growing Up in New Zealand* Kaitiaki/Guardianship principles which cover:

- Culturally appropriate analyses and interpretation of data.
- Benefits and risks for Māori and other cultural groups.
- Acknowledgement of data as taonga.
- The imperative to protect and value these data for the benefit of Māori and other cultural groups.

The *Growing Up in New Zealand* Kaitiaki Advisory Group is in place to ensure that the approach of the study is consistent with the Kaitiaki Principles. This means that the collection, storage, and use of Māori data is compatible with Māori development goals and aspirations.

## Your right to no longer participate in the study

You can choose to stop participating in the *Growing Up in New Zealand* study at any time. If you decide to take part in the 15 Year Catch-Up but change your mind later, then you can let us know. You can contact the *Growing Up in New Zealand* team at [contact@growingup.co.nz](mailto:contact@growingup.co.nz) or 0508 GROWING UP (0508 476 946) to inform us that you no longer wish to take part in this data collection or the study. The *Growing Up in New Zealand* study team will then stop contacting you and stop collecting information from you.

Information collected from you up until the time you choose not to participate in the study will continue to be used and included in study research. If you wish, you may ask for this information to be removed from the research data. It will not be possible to remove your data from any projects that have already analysed your data. However, no future projects will use your data.

If requested, samples such as saliva and skin microbiome swabs collected prior to you opting out of participating in the study will not continue to be used and analysed. Samples collected and/or stored for future research can be destroyed if you request this (with a karakia, if you wish).







## How do we add additional information to the study?

Previously in this study we have asked for consent to link your young person's *Growing Up in New Zealand* information with other routinely collected government data sets, such as health and education information.

This is called 'data linking'. Data linking in this study has always been optional and you will be asked to consent to data linking as part of the consent process each time we wish to collect this information. At the 15 Year Catch-Up we are not asking you to consent to linking.

## Where can I find out the results of the study?

Every few years, *Growing Up in New Zealand* produces a report or a series of reports which summarises the latest findings from the study. These are provided to the New Zealand government and other agencies for use in the development of policy and other services.

The findings of other researchers who use *Growing Up in New Zealand* data are also regularly published and are often featured in the media.

You can find out about all the latest research on our website, [www.growingup.co.nz](http://www.growingup.co.nz).

We also share findings in our regular newsletters and on our social media.

## 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).

## Who do I contact for more information or if I have concerns?

If you have any questions, concerns, or complaints about the study at any stage, please contact a team member from *Growing Up in New Zealand*.

Phone 0508 GROWING UP (0508 476 946) or email [contact@growingup.co.nz](mailto:contact@growingup.co.nz). More information about the study is available at [www.growingup.co.nz](http://www.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. Phone 0800 555 050, or email [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz).

You can also contact the Ethics Committee that reviewed and approved this study on 0800 4 ETHICS (0800 438 4427), or email [hdec@health.govt.nz](mailto:hdec@health.govt.nz).



## Further contacts if you want to talk to someone

If any of the questions you answer in the *Growing Up in New Zealand* questionnaire have made you feel upset or worried, or raised any issues you would like to discuss with someone outside of the study team, the following organisations may be able to help.

- **Parent Helpline** on 0800 568 856 (9am to 9pm) if you need parenting advice, or see the website [www.parenthelp.org.nz](http://www.parenthelp.org.nz)
- **Healthline** on 0800 611 116 if you need health advice about your young person/people
- **Need to talk?** Free call or text 1737, 24 hours a day to talk to (or text with) a trained counsellor or talk to a peer support worker, or visit [1737.org.nz](http://1737.org.nz)
- **Depression Helpline**, free phone 0800 111 757
- **Anxiety Line** 0800 ANXIETY (2694 389)
- **Alcohol Drug Helpline** 0800 787 797
- **Gambling Helpline** 0800 654 655
- **Quitline** for support to stop smoking 0800 778 778
- **Rural Support Trust** 0800 787 254
- **Lifeline** telephone counselling service and text line provides 24 hours a day, 7 days a week counselling and support.  
Phone 0800 543 354 (0800 LIFELINE) or text "Help" to 4357
- **Women's Refuge** on 0800 733 843
- **Moneytalks** is a free and confidential helpline for people experiencing financial hardship. Moneytalks can provide advice on budgeting, bills, debt, loss of income etc. to individuals, family and whānau. Phone 0800 345 123 or visit [www.moneytalks.co.nz](http://www.moneytalks.co.nz).
- There is also **Youthline** which is a 24/7 "with youth, for youth" organisation that supports young people aged between 12-24 years throughout Aotearoa New Zealand.  
Free 24/7 call 0800 37 66 33 or Free 24/7 text 234. Email [talk@youthline.co.nz](mailto:talk@youthline.co.nz) or chat online at [youthline.co.nz](http://youthline.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:

Associate Professor Sarah-Jane Paine

Study Site:

The University of Auckland, Private Bag 92019, Auckland 1142, New Zealand

Ethics committee ref.:

NTY/08/06/055/AM20