



Waipapa
Taumata Rau
University
of Auckland

 **Growing Up**
in New Zealand

A young man with curly brown hair is sitting on a wooden fence in a park. He is wearing a dark green zip-up jacket, black shorts with white stripes, and black socks. He is looking towards the camera with a slight smile. The background shows green grass, trees with yellowing leaves, and a clear blue sky.

Participant Information Sheet Young People

Sharing *Growing Up in New Zealand* data with Stats NZ

We want to ask your permission to share a copy of the data collected about you as part of the *Growing Up in New Zealand (GUINZ)* study with Statistics New Zealand (Stats NZ) so that it can be used by researchers in the Stats NZ Integrated Data Infrastructure.

Sharing your data with Stats NZ would mean that researchers could join your data with other types of data collected by the government to help improve the health and wellbeing of children, young people, and their families/whānau in Aotearoa New Zealand.

What is Stats NZ and what is the IDI?

Stats NZ is the New Zealand government's official data agency (stats.govt.nz). They collect information from people and organisations through censuses and surveys. They use this information to publish insights and data about New Zealand, and support others to use the data.

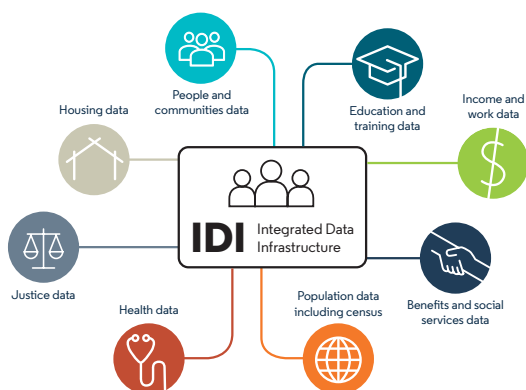
The Integrated Data Infrastructure (IDI) is a large Stats NZ research database that contains information about everyone who lives in New Zealand. If you've had contact with organisations that provide data to the IDI, such as Health, Education, Work and Income, Justice, and Immigration, then it is likely there is already information about you in the IDI. The IDI also holds survey information, from the census, and other household and personal information such as tax, income and housing details.

The different types of datasets and information on individuals and households held in the IDI is shown in the following diagram:

Data in the IDI March 2024

Stats NZ
Tātauranga Aotearoa

Stats NZ's Integrated Data Infrastructure (IDI) is a large research database containing de-identified microdata about people and households.



Health data

- B4 School Checks – from 2008
- Cancer registrations – from 1995
- Chronic conditions – pre 1985
- General medical services claims – from 2002
- Health Tracker – 2006–2014
- Immunisation – from 2005
- InterRAI – from 2014
- Laboratory claims – from 2003
- Maternity – from 2003
- Mortality – from 1988
- National Booking Reporting System – from 2003
- National Needs Assessment and Service Coordination Information System (SOCRATES) – from 1988
- National non-admitted patient collection – from 2007
- NES enrolments – from 2019
- New Zealand Health Survey – from 2011
- Pharmaceutical – from 2005
- PHO enrolments – 2003–2018
- Population cohort demographics and addresses – from 2003
- PRIMHD – from 2008
- Privately funded hospital discharges – from 2001
- Publicly funded hospital discharges – from 1988

Education and training data

- Early childhood education participation – from 2006
- Industry training – from 2001
- Schooling data – from 2004
- Targeted training – from 2001
- Tertiary Education – from 1994
- Programme for the International Assessment of Adult Competencies – 2014

Benefits and social services data

- Injury claims data – from 1994
- Early Start Project – from 2016
- Working for Families – from 1999
- Benefits – from 1990
- Child, Youth, and Family – from 1991
- Children's Action Plan – from 2013
- Family Start – from 2008
- Youth services – from 2004
- Student loans and allowances – from 1992

Justice data

- Sentencing and remand – from 1998
- Court charges – from 1992
- New Zealand Crime and Victims Survey – from 2018
- NIA links – from 2009
- Recorded crime: offenders – from 2009
- Recorded crime: victims – from 2014

People and communities data

- Auckland City Mission – from 1996
- Migrant Survey – 2012
- Drivers licence and motor vehicle registers – from 2006
- Disability Survey – 2013
- General Social Survey – from 2008
- Longitudinal Immigration Survey of NZ – 2005–2009
- Te Kupenga – 2013 and 2018

Population data

- Border movements – from 1997
- Births, deaths, and marriages – from 1840
- Civil unions – from 2005
- Border movements – from 1997
- Visa applicants – from 1997
- Census – 2013 and 2018

Income and work data

- Tax and income – from 1999
- Household Economic Survey – from 2006
- Household Labour Force Survey – from 2006
- NZ Income Survey – from 2006
- Survey of Family, Income, and Employment – 2002–2010

Housing data

- Tenancy – from 2000
- Social housing – from 2000

The IDI contains person-centred microdata from a range of government agencies, Stats NZ surveys including the 2013 Census, and non-government organisations. For more information about data in the IDI, see

www.stats.govt.nz/integrated-data/integrated-data-infrastructure

The Longitudinal Business Database (LBD) complements the IDI with microdata about businesses. For more information about data in the LBD, see

www.stats.govt.nz/integrated-data/longitudinal-business-database



Stats NZ operates a five-safes environment, balancing privacy and confidentiality with data insights.

For information about applying to use the IDI or to learn about how we keep the data safe, see www.stats.govt.nz/integrated-data

Researchers can apply to use the IDI for research in the public interest to help answer questions about complex issues that affect New Zealanders.

All the information in the IDI is de-identified. This means that names or other personal details are not attached to your information, so you cannot be individually identified to anyone using the database.

You can find more information about the IDI via a link at the bottom of this information sheet.

What information would be shared?

The GUINZ study has been collecting a 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.

Here are some examples of the types of information we would share with Stats NZ for researchers to use in the IDI.

Demographics

e.g. your ethnicity, sex at birth

Use of health services and other government agencies

e.g. GP, immunisations, other health checks

Housing & neighbourhood

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

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

Sleep, activity and diet

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

Health and wellbeing

Your 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

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

We would also need to share your National Health Identification (NHI) number and date of birth with Stats NZ so that they can join (or “link”) your *GUINZ* data to other information about you and your household that has been collected by government. The NHI number is a unique number that is given to every person who uses health and disability services in New Zealand. Once this linkage is done, your NHI would be encrypted, which means the numbers are changed so that the information could not be connected back to you. This is a security measure to ensure that all of your information is de-identified and private.

Once you have consented to sharing your data with Stats NZ for integration into the IDI, it can't be removed.

Your data will be de-identified during integration and before anyone can use it. This involves Stats NZ removing or masking identifying information, like your name, so that no one can readily identify that any one piece of data belongs to you. Stats NZ can't practically undo this process to remove a single person's data. However, you will have the opportunity to opt-out of sharing any future data as part of any new *GUINZ* data collection waves.

A full list of all the information we have collected about you and your household are available via a link at the bottom of this information sheet.

What information would not be shared with Stats NZ?

Here is a list of information that will not be shared with Stats NZ:

- Your names, contact information, physical address
- Biological samples and their associated data (including things such as Guthrie newborn metabolic screening, saliva samples, swabs, and DNA)
- Audio recordings and transcriptions
- Responses to the open-ended questions in the surveys (such as: what are your hopes for the future?)
- Any details provided to *GUINZ* by your primary caregivers and/or your caregivers partner or your teachers

What are the benefits of sharing my *Growing Up in New Zealand* data with Stats NZ?

The IDI is becoming NZ's major source for answering important policy questions. You can find some examples of the types of research that are possible in the IDI via a link at the bottom of this information sheet.

Sharing a copy of your *GUINZ* data with Stats NZ would mean that researchers can answer a wider variety of questions about what matters most for children's health, development, and lived experience than is possible using the *GUINZ* data by itself. Ensuring that children and young people's experiences are included in research and policy-making in NZ has been an important part of the *GUINZ* study since the very beginning.

What are the risks of sharing my *Growing Up* information with Stats NZ?

The potential risks of sharing your data with Stats NZ's IDI are similar to those that already exist for the *GUINZ* study as a whole. However, the possibility of these risks occurring could slightly increase as your data will be joined with many other databases that are available

in the IDI, as shown in the diagram above. *Growing Up in New Zealand* and Stats NZ have worked together to identify the potential risks, including:

- 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 Stats NZ database
- The possibility data is used for non-approved purposes, i.e. data is shared with someone/group who is not an approved researcher.
- The 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.

Stats NZ has a plan for each of these risks and works hard to ensure they do not occur. For example, researchers who break Stats NZ protocols can be banned, blacklisted or prosecuted. More information about what Stats NZ do to keep your data safe can be found via a link at the bottom of this information sheet.

Who will be responsible for looking after my *Growing Up* data?

The University of Auckland and Stats NZ have created a Data Sharing Agreement which sets out our commitment to work together to ensure that your data remains safe and secure and the rules around how it can be used for research in New Zealand

If you give permission for your data to be shared, then the *Growing Up in New Zealand* team will transfer your data to Stats NZ using a secure transfer process. Once your data has been transferred then it would be under Stats NZ's guardianship which means Stats NZ would be responsible for storing it securely, protecting it, and looking after it. Stats NZ would also be responsible for ensuring that any research that uses *GUINZ* data is in the best interests of the public and that approved researchers use the data safely. The *GUINZ* data will appear as additional datasets in the Stats NZ IDI. Researchers will submit their research questions to Stats NZ, and if they are approved, the researchers will be able to join the *GUINZ* data to any of the relevant datasets held in the IDI.

Stats NZ will also recommend that researchers contact specialists from the *GUINZ* team at the University of Auckland to ensure that the research will help children and young people in New Zealand. The *GUINZ* team will not make any decisions about which researchers can access your data and what projects are approved. Stats NZ will be responsible for making those decisions.

No matter what you decide, a full copy of all your data will continue to be stored at the University of Auckland under the guardianship of *GUINZ*. Researchers will be able to continue accessing a copy of the full data by applying to the *GUINZ* team and we will continue to make decisions about the types of research that can be done with your data held at the University. Some examples of projects that have been approved for use at the University can be found via a link at the bottom of this information sheet.

How should we decide what to do?

The first thing to know is that there is no right or wrong way to decide about sharing your data with Stats NZ.

We know that a lot of young people in the study will feel ready to make this decision by themselves and that is great. However, we also know that being part of the *GUINZ* 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.

Because of this, we will also be asking your mother/primary caregiver to provide their permission for your information to be shared with Stats NZ. We will only share your data with Stats NZ if you and your mother/

primary caregiver both agree to this request. It is ok to have a different opinion to your mother/primary caregiver, and if that happens, we will not share your data with Stats NZ.

We want to encourage you to talk to your parent/caregiver about this request. 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.

Here are some prompts you could use if you think that talking to someone would be helpful for you:

- Why did you decide to sign-up for this study? Why was it important to you?
- What kind of data do they have about me/us? Do you remember? (Don't forget, you can find the full list of information that we would be sharing with Stats NZ via a link at the bottom of this information sheet)
- What do you think researchers do with our data?

What happens if I don't want my *Growing Up in New Zealand* data to be shared with Stats NZ?

You can say no to this request if you want to. That is ok. Saying no will not change your participation in *GUINZ*.

If you say no then we will not share any of the information that *GUINZ* has collected about you with Stats NZ, even if your mother/primary caregiver tell us they are ok with it. Your information would stay stored at the University of Auckland where we will continue to take care of it and make decisions about how it is used for research and policy.



More about GUiNZ

The *Growing Up in New Zealand* study is hosted by Waipapa Taumata Rau | The University of Auckland and led by a team of researchers based at the Faculty of Medical and Health Sciences, Grafton Campus, Auckland. The contact details for the Research Director and other key personnel at the University can be found below. The GUiNZ 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 Health and Disability Ethics Committee has approved this proposal (NTY/08/06/055/AM0434).

Funding for the *Growing Up in New Zealand* study has been provided, primarily, by the New Zealand government, including the Ministry of Social Development who have managed the Crown funding for *Growing Up in New Zealand* as well as from the Ministries of Health and Education, as well as Oranga Tamariki; Te Puni Kōkiri; the Ministry of Justice; the Ministry of Business, Innovation and Employment; the Ministry for Pacific Peoples; the Ministry for Women; the Department of Corrections; the New Zealand Police; Sport New Zealand; and the Office of the Health and Disability Commissioner.

Any more questions?

Here are some of the places you can go for help with any questions:

- Our freephone number is: 0508 GROWING UP (0508 476 946)
- Our website is: growingup.co.nz/idi-linkage
- More information on Stats New Zealand and the IDI is available from stats.govt.nz/idi

If you have any questions, concerns or complaints about the study in general, or about this proposal, you can contact any of the following people:

Associate Professor Sarah-Jane Paine
GUiNZ Research Director and Principal Investigator
Telephone number: 09 373 7599
Email: directorgrowingup@auckland.ac.nz

Dr. Carin Napier
GUiNZ Research Delivery Manager
Telephone number: 0508 476 946
Email: researchgrowingup@auckland.ac.nz

Karleen Edmonds
GUiNZ Cohort Relationship manager
Telephone number: 0508 476 946
Email: contact@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: hdec@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/AM0434). 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.

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|------------------------|---|
| Formal Study title: | <i>Growing Up in New Zealand</i> |
| 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/AM0434 |



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