

COVID-19 Wellbeing Survey Data User Guide

November 2021



THE UNIVERSITY OF
AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau
NEW ZEALAND

Table of Contents

1. Purpose of document	4
1.1 Background to the <i>Growing Up in New Zealand</i> cohort study.....	4
1.2 Background to the Growing Up in New Zealand DCWs	5
1.2.1 Timelines	5
1.2.2 Face-to-face interviews	5
1.2.3 Telephone interviews	6
1.2.4 Online questionnaires	6
1.2.5 Self-completion paper-based diary	6
1.2.6 Data linkage.....	6
1.3 Background to the COVID Wellbeing Survey	7
2. Design of the COVID Wellbeing Survey	8
2.1 Eligibility criteria	8
2.2 Data collection process.....	8
2.3 Survey questions.....	8
2.4 Tools and instruments used in the COVID Wellbeing Survey.....	11
3. Survey completion	13
3.1 Question completion rates	13
3.2 Baseline demographics	17
4. Utility and benefits	21
5. Limitations of the data	22
5.1 Different data collection process to previous DCWs	22
5.2 Response bias	22
5.3 Reporting bias.....	22
5.4 Question comparison with previous DCWs	22
5.5 Age.....	23
5.6 Activity participation.....	23
5.7 Media use and screen time questions	23
5.8 Depression scale	23
5.9 Anxiety scale	23
5.10 School satisfaction instrument	24
6. Growing Up in New Zealand reference publications	25
7. Preparation of external datasets	29
7.1 Data anonymisation.....	30
7.2 Additional considerations when planning data analysis	31

7.2.1	Data preparation	32
7.2.2	Exploratory data analysis.....	33
7.3	Data use disclaimer.....	33
8.	Protecting participant anonymity	34
8.1	Study principles and participant consent.....	34
8.2	The Data Access Protocol.....	34
8.3	The Data Access Committee	35
8.4	Data security requirements	35
9.	References	36

1. Purpose of document

This document provides a data user reference guide for researchers interested in using anonymised *Growing Up in New Zealand* data from the bespoke COVID Wellbeing Survey and linking the data to other *Growing Up in New Zealand* datasets (collected from before the cohort children were born up to and including up to when they were approximately eight years old).

This document provides: background to the *Growing Up in New Zealand* study; available external datasets; and information about the COVID Wellbeing Survey dataset (including the questions asked, data collection processes; summary of processes to prepare the dataset and its structure and content; information about utilizing the dataset; and how to apply for data access and expectations regarding dataset use). Research data available for release from the Survey have been anonymised to protect participant privacy and to comply with participant consents.

Note this reference document is designed to be read and used in conjunction with:

- The COVID Wellbeing Survey Questionnaire
- the *Growing Up in New Zealand* questionnaires used to collect information at Data Collection Waves (DCWs)
- Data dictionaries for each component of each of the DCWs
- the descriptive “Now We Are” reports
- Contextual reference documents, reports and papers listed in this document and available at www.growingup.co.nz

The above documents are also presented and discussed at data access workshops held for all potential data users and data access applicants. These workshops are recorded and made available online at www.growingup.co.nz. Application should be made to the *Growing Up in New Zealand* team directly via dataaccess@growingup.co.nz. All potential users should attend or familiarize themselves with these resources and the workshop materials to assist them with making applications to use datasets.

The overarching aim of providing these documents is to enable potential data users to access sufficient information to enable them to apply to use the *Growing Up in New Zealand* datasets for bona fide research projects.

1.1 Background to the *Growing Up in New Zealand* cohort study

Growing Up in New Zealand is a child-focused 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. At baseline 6853 children and their families were recruited into this study, during the cohort mothers’ pregnancy.

The overarching study aim of *Growing Up in New Zealand* is to provide a more complete picture of the pathways that lead to successful and equitable child wellbeing development in the context of growing up in the contemporary Aotearoa New Zealand environment.

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. For further information on study design and sample collection refer to: 1) the publication in the International Journal of Epidemiology detailing the cohort profile, recruitment and retention (see Section 5 for the full reference); and 2) the Calibration Protocol: Technical Working Document (available at www.growingup.co.nz).

1.2 Background to the Growing Up in New Zealand DCWs

Each DCW for *Growing Up in New Zealand* seeks information across six inter-connected domains (Family and Whānau; Societal Context; Education; Health and Wellbeing; Culture and Identity; Psychosocial and Cognitive Development) and themes (Māori; Asian; Pacific and European). Each cross-sectional DCW is planned accordingly to collect a balanced set of age-appropriate information across the inter-connected domains, in the context of the overarching longitudinal research objectives, whilst also aiming to collect information with policy relevance. Attention is also given to ensuring that the tools employed to collect domain-specific information takes due account of the unique Aotearoa New Zealand population and environmental context.

1.2.1 Timelines

The *Growing Up in New Zealand* cohort study was commissioned by the Aotearoa New Zealand government in 2004 and commenced in 2008, with the recruitment of 6822 pregnant mothers who had an expected due date between March 2009 and May 2010. A cohort of 6853 children were born into the study. Longitudinal information has been collected from participating children and their families at several time points and from multiple sources (mother, partner, child proxy and child observation data) and via different collection methods including face-to-face interviews, telephone interviews, and data linkage.

1.2.2 Face-to-face interviews

Computer Assisted Personal Interviews (CAPI) were undertaken by trained interviewers, most often in the child’s home, at several time points including:

- The antenatal DCW0 with the pregnant mother (most often in the last trimester of her pregnancy) and with her partner (almost always the stated biological father);
- The nine month DCW1 with the child’s mother and her partner;
- The two year DCW2 with the child’s mother and her partner, which also involved direct observations, developmental and anthropometric assessments of the children at two years of age;

- The four year (pre-school) DCW5 with the child's mother, which included direct observations;
- Developmental and anthropometric assessments and biological samples from the children at four years of age;
- The eight year DCW8 with the child, which included direct observations, developmental and anthropometric assessments and biological samples from the children at eight years of age.

1.2.3 Telephone interviews

Brief Computer Assisted Telephone Interviews (CATI) were undertaken by trained staff with the child's mother (or equivalent) to allow for age-appropriate developmental information to be collected and to assist with cohort retention. These phone calls occurred at several time points including when the children were:

- 6 weeks old
- 35 weeks old
- 16 months old
- 23 months old
- 31 months old
- 45 months old

1.2.4 Online questionnaires

Self-completed online questionnaires were used when the children were:

- 72 months old: the child's mother answered a single questionnaire.
- 8 years old: the child's mother completed both the 'child proxy' and 'mother' questionnaires.

1.2.5 Self-completion paper-based diary

Completion of a Time Use Diary (TUD) required the participant to record every activity performed on the specified days. Participants were asked either to complete the diary as they are performing activities throughout the day, or to recall their activities at regular intervals during the day or at the end of the day:

- 8 years old: the child completed the TUD over two days: one day during the week and one day during the weekend.

1.2.6 Data linkage

Parental consent for data linkage is sought at strategic times to enable self-reported information to be supplemented by information from routine health data. Once consent is obtained, further resources (and

time) are required to undertake data linkage and create derived variables that have utility for all users. Once completed these derived variables, and the associated technical documentation, is made available in the external datasets.

1.3 Background to the COVID Wellbeing Survey

The first case of COVID-19 in NZ was identified on the 28th February 2020.¹ The NZ Government's response to COVID-19 was fast and effective, with border entry measures immediately implemented. In March 2020, the Aotearoa New Zealand Government introduced a four-level COVID-19 alert system, with each level considering the immediate level of risk and outlining the required restrictions that legally had to be followed to minimise the risk of catching and/or spreading COVID-19. As the levels increased, restrictions increased on population movement, travel, and gatherings. The alert levels were Level 1 (Prepare), Level 2 (Reduce); Level 3 (Restrict); and Level 4 (Lockdown).

A summary of the alert levels is below:²

- **Alert level 1 (Prepare):** No restrictions on movement, domestic travel or gatherings. All educational facilities, public venues and businesses are open. People are encouraged to maintain records to enable contact tracing.
- **Alert level 2 (Reduce):** People are able to mix with friends and family. Educational facilities, business and public venues can open, but with physical distancing. Gatherings of up to 100 people are permitted. Sport and recreation activities are permitted. Inter-regional travel is permitted. Face coverings are required on public transport and aircraft (with some exemptions). People are encouraged to maintain records to enable contact tracing.
- **Alert level 3 (Restrict):** All people are advised to stay at home in their immediate household unit or 'bubble', but the bubble can include external caregivers, close family, or isolated people. Only essential movement is permitted, but safe recreational activity is allowed in the local area with physical distancing. Children should be schooled at home, but educational facilities can open with limited capacity. Public venues are closed. Businesses can open provided they have no physical interaction with customers. Gatherings of up to ten people are permitted but only for certain events. Inter-regional travel is restricted. People are encouraged to maintain records to enable contact tracing.
- **Alert level 4 (Lockdown):** All people are advised to stay at home in their immediate household 'bubble', except for essential movement, although safe recreational activity is permitted in the local area with physical distancing. All educational facilities, public venues and all businesses must close, except essential services. Gatherings are cancelled and travel is significantly restricted. People are encouraged to maintain records to enable contact tracing.

At 11:59pm on the 25th March 2020, in response to a rapid increase in the number of COVID-19 cases in the country, the whole of Aotearoa New Zealand moved to Alert Level 4. This lockdown continued until 11:59pm on the 27th April 2021, whereupon the whole country was dropped back to Alert Level 3. At 11:59pm on the 13th May 2020, Aotearoa New Zealand dropped back to Alert Level 2. The COVID Wellbeing Survey discussed in this document was delivered during COVID Alert Levels 2 and 3.

2. Design of the COVID Wellbeing Survey

An online COVID Wellbeing Survey was delivered between the 8th - 24th May 2020 and completed by 2,421 children aged 10-11 years participating in the *Growing Up in New Zealand* longitudinal study.

The survey provided the opportunity to see how well a child-centred digital engagement process would connect with existing GUINZ parent-based digital contacts for cohort members, noting that primary contacts for families were previously residential address-based. Information on the level of engagement by cohort children in an online survey is important to know for future data collection exercises where face-to-face data collection is not possible or preferred. The survey also provided the opportunity to determine the children's experiences during Alert Levels 2 - 4, including their health and mental wellbeing, schooling, connectedness, media use, and nutrition; and compare findings to information collected from previous DCWs..

The COVID Wellbeing Survey was the first time the *Growing Up in New Zealand* cohort children completed their own questionnaire online. Ethical approval for the survey was obtained from the Northern B Health and Disability Ethics Committee on the 29th of April 2020 (NTY/08/06/055 AM15).

2.1 Eligibility criteria

Children were eligible if: the person who had completed the "Mother questionnaire" at the most recent DCW the child had taken part in, had not withdrawn from the *Growing Up in New Zealand* study prior to May 2020; this person had a contact email address, and the child was living in Aotearoa New Zealand at the time of survey distribution. Children whose caregivers had requested that all communications be in Te Reo Māori (the language of the indigenous Māori people of Aotearoa New Zealand) were ineligible for the survey, as translation of the survey was unfortunately not possible given time constraints.

2.2 Data collection process

Email invitations to participate in the survey were generated from the Qualtrics® digital platform and sent to the person who had completed the "Mother questionnaire" at the most recent DCW the child had taken part in (and had not withdrawn prior to May 2020 and had a contact email address). The invitation included an individualised link to the survey, which directed them to a web-based online survey accessible on all devices (computer, tablet, phone).

The front page of the survey described the purpose of the questionnaire and gave children the opportunity to accept or decline to participate. Children could complete the survey independently or receive help from a family member if required. To increase compliance with survey completion, a general media campaign promoting the survey to *Growing Up in New Zealand* participants was run whilst the survey was live. No koha was offered to participants for questionnaire completion.

2.3 Survey questions

The survey consisted of 46 questions. A summary of the data available is shown below. This information

should be read in conjunction with the survey questionnaire. Questionnaires from previous DCWs and associated data dictionaries are also relevant reference documents, if data linkage across DCWs is of interest.

- **Consent and name** (Questions 1-2 in the survey).
- **Age:** in years (Questions 3-4 in the survey). Other demographic variables are available from previous DCWs via data linkage.
- **COVID-19 ‘Bubbles’:** (Questions 5-14 in the survey). The term ‘bubble’ is used to describe a household unit which is self-isolating. During the COVID-19 Level 4 (Lockdown) people in Aotearoa New Zealand were instructed to stay at home only with those in their bubble and restrict contact with other bubbles. Questions asked: How many people were living in the household at the time of the survey; How many bubbles the child was in at the beginning of lockdown and if more than one, How often they moved between bubbles (Every day; Every week; Less often); and Who was in each bubble (their relationship with the child, their age, whether they lived with the child before lockdown; whether they looked after the child, and whether they had to leave the bubble to work somewhere else).
- **Positive childhood experiences:** (Question 15 in the survey). Children were asked how often during lockdown they had: Felt able to talk to someone about their feelings; Felt their family supported them in this time; Participated in community activities within their bubble; Felt connected to school/kura; Felt able to keep in touch with friends; Felt safe and protected in their home; and Felt worried about how people in their home were getting on. Each statement had six options for answering (Never; Almost never; Sometimes; Often; Always; I don’t know). These seven questions were adapted from (but are not exactly the same as) the Positive Childhood Experiences Score, which was adapted from four subscales included in the validated “Child and Youth Resilience Measure–28”.⁶
- **Material wellbeing:** (Question 16 in the survey). Children were asked how often they worried about how much money their family had, with six options available for answering (Always; Often; Sometimes; I never think about it all; I don’t know).
- **Family, play and safety:** (Question 17 in the survey). Children were asked about how much they agreed with the following statements: My parents (or the people who look after me) listen to me; We have a good time together as a family; In my bubble there are enough places to play or to have a good time; and I feel safe when I am out and about in the area I live in. Each statement had six options for answering (I do not agree; Agree a little bit; Agree somewhat; Agree a lot; Agree totally; I don’t know).
- **School satisfaction:** (Questions 18-20 in the survey). Children who were currently still doing schoolwork at home in their bubble were asked how often the following statements were true: I look forward to doing school-work in my bubble; I like school work in my bubble; School work in my bubble is interesting; I wish I didn’t have to do schoolwork while in my bubble; There are many things about school in my bubble that I like; I enjoy the school activities I do in my bubble; I am

looking forward to going back to how school was before we had lockdown; I am worried about missing out on my usual schoolwork while we are in lockdown. Children who had gone back to school were asked the same questions but were asked to reflect back to the time when they were still doing schoolwork at home in their bubble (i.e., questions were framed in the past tense). The questions were derived from the Multidimensional Students Life Satisfaction Scale (MSLSS)7 – refer to Table 1 for more detail. Each statement had five options for answering (0= Never; 1= Sometimes; 2 = Often; 3 = Almost always; I don't know). People who answered "I don't know" were assigned a 'data missing' status for the statement. A school satisfaction score was then derived for each participant by summing the responses for each item (after reverse coding of negatively worded questions) then dividing by the total number of questions. Higher scores are associated with higher school satisfaction, and the scores are used as a continuous scale with no cut-off.

- **Current health:** (Question 21 in the survey). Children were asked how their health was right now, with five options provided for answering (Excellent; Very good; Good; Fair; Poor).
- **Current media use:** (Questions 22-27 in the survey). Children were asked about their current access to the internet, and whether they had access to a device during lockdown (including types of devices, whether these devices had access to a camera, and what activities they used these devices for). Children were also asked whether they currently belonged to, or used, any social media sites.
- **Connectedness:** (Questions 28-33 in the survey). Children were asked whether they had any contact with friends outside of their family, or family not living with them, during lockdown, and if so what type of contact and how frequent this contact was (Everyday; A few times a week; Weekly; Fortnightly; Less than fortnightly; Only once or twice).
- **Screen time:** (Questions 34-35 in the survey). Children were asked about their screen time during lockdown, on a school day and the weekends (defined as hours per day spent on screens, including schoolwork).
- **Depression:** (Question 36 in the survey). Statements related to depressive symptoms in the past seven days. Each question had a 4-point Likert scale for answering (0 = Not at all; 1 = A little; 2 = Some; 3 = A lot). A total score is then calculated by summing the score of all items, after reverse coding of the two positive affect statements ('I felt like something good was going to happen' and 'I was happy'). Total scores can range between 0 and 30, with higher total scores indicating a greater risk of depressive symptoms (scores of ≥ 10 are indicative of clinically significant depressive symptoms).³
- **Anxiety:** (Question 37 in the survey). Statements related to anxiety symptoms in the past seven days. Each item was scored on a 5-point Likert scale (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost always). A total score is calculated by summing the score of all items. The total score is then translated to a T-score, using a score translation table that has been generated based on item-response theory. The standardised T-score has a mean score of 50 (Standard Deviation [SD]=10) for the reference population, which is a mix of the 'general population' (based on the 2000 General USA census) and a clinical sample of chronically ill children.⁴⁻⁵ Scores >50 therefore lie above the reference population mean, and scores <50 are below the reference population mean. Scores of 51-55 indicate 'mild' symptoms of anxiety. Scores of 56-65 indicate

‘moderate’ symptoms of anxiety. Scores >66 indicate ‘severe’ symptoms of anxiety.

- **Activities during lockdown:** (Question 38 in the survey). Children were asked how often they did the following activities with the people in their bubble during the lockdown: Reading books together; Watching television/movies together; Talking about feelings or issues; Singing a song, playing music, or doing some other musical activity; Drawing a picture or doing another art/craft activity; Homework and/or school work or talking about homework or school work; Outdoor sporting activities together; Baking or cooking together; Doing chores or housework together; Eating a meal together. Each question had six options for answering (Never/Almost never; Once a week; Several times a week; Once a day; Several times a day; I don’t know).
- **Food and drink during lockdown:** (Questions 39-41 in the survey). Children were asked which of the following statements were true about the food and drinks they had during the lockdown: I eat more food than before; I eat more often during the day than before (more meals and snacks); I eat more fruit than before; I eat more vegetables than before; I eat more potato chips, chocolate, biscuits, cake or lollies; I drink more fizzy drink than before; I drink more water than before; I eat a greater variety (different types) of food than before. Each statement had six options for answering (I do not agree; Agree a little bit; Agree somewhat; Agree a lot; Totally agree; I don’t know). Two additional questions were asked around what the child liked most about the food in their bubble, and what foods they missed most in their bubble. Both questions had a free text option for answering.
- **Feelings during lockdown:** (Questions 42-46 in the survey). The last questions of the survey asked what the child felt had been the best thing for them about being in lockdown, plus what had been the hardest, and what they had most worried about. The child was also asked what they were most excited for/about when lockdown was over. Finally, the child was asked if there was anything else they wanted to share with other people about what it was like to be in lockdown for them. All five questions had a free text option for answering.

2.4 Tools and instruments used in the COVID Wellbeing Survey

The COVID Wellbeing Survey used several tools and scales. Validated scales were used where feasible and may have been adapted according to the context of the survey.

Table 1 provides summary information on the tools and scales used in the survey to assist users of the dataset. The table contains information to assist users by providing.

Table 1: Tools and scales used in the COVID Wellbeing Survey

Question & variable code	Topic	Tool or scale	Notes
Q 18-20 (Variable NCCQ_SCORE_Y1 1LDC)	School satisfaction	Multidimensional Students Life Satisfaction Scale (MSLSS). ⁷	The questions were derived from the six items with the highest factor loadings from the original 8-item MSLSS, as identified by Rowe et al. ⁸ Previously this scale has been

Question & variable code	Topic	Tool or scale	Notes
			referred to in <i>Growing Up in New Zealand</i> publications as 'Class Climate'.
Q 36 (Variable DEPRESS_SCORE_Y11LDC)	Depression	The validated 10-item short form ²¹ of the Center for Epidemiological Studies Depression Scale (CES-D-10). ³	A publication is currently being prepared which validates this questionnaire for the <i>Growing Up in New Zealand</i> cohort at age 8.
Q 37 (Variable PAS_T_SCORE_Y11LDC)	Anxiety	The validated 10-item short form of the PROMIS Pediatric Anxiety Symptoms Scale. ⁹	Interpretation of the T scores was based on the 'Interpreting PROMIS T scores' diagram. ¹⁰

3. Survey completion

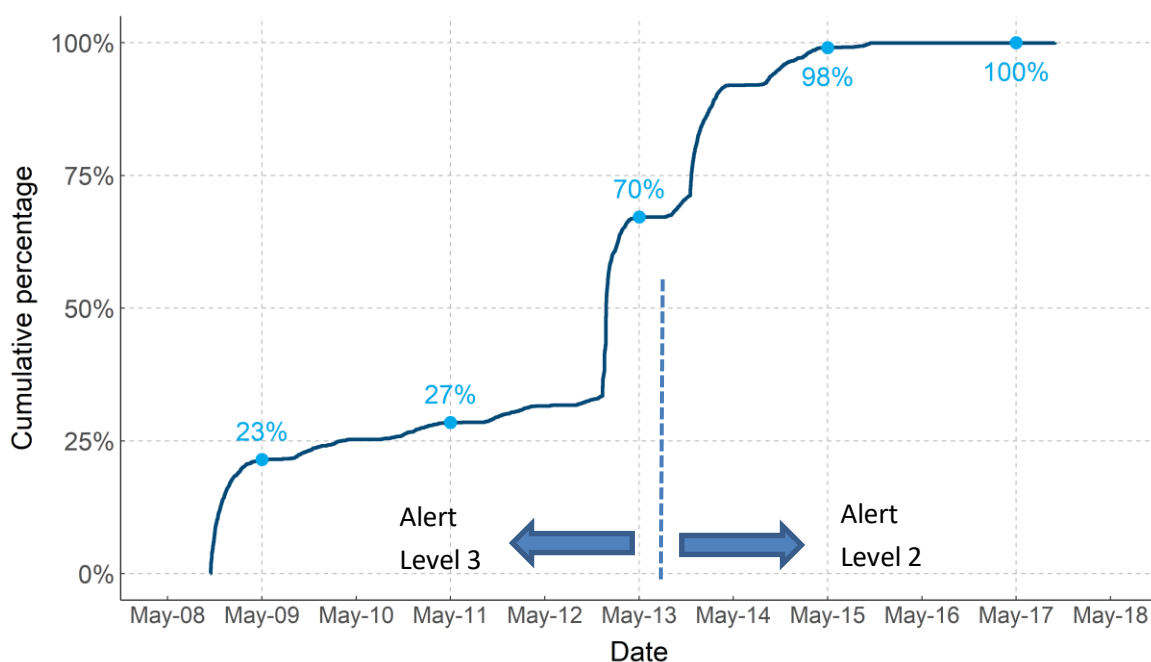
The COVID Wellbeing Survey was the first time the *Growing Up in New Zealand* cohort children completed their own questionnaire online.

In total, 5756 *Growing Up in New Zealand* children were deemed eligible to participate in the Survey, which went live on the 8th May 2020. At that time Aotearoa New Zealand was at Alert Level 3, 12 days after stepping down from Alert Level 4.

It was originally planned for the live link to remain open for seven days. However, a small number of children declined to participate when they had not meant to do so. Their parents contacted the study team and asked for the children to be re-issued a survey link, which extended the period of data collection. The survey was closed on the 24th May 2020 when Aotearoa New Zealand was at Alert Level 2.

Overall, 2421 children completed the survey giving a response rate of 42%, which is considered high for a digital survey.¹⁶ Overall, 70% (1694) of the children completing the survey during Alert Level 3, and 30% (727) completing the survey during Alert level 2 (Figure 1).

Figure 1: Recruitment summary



3.1 Question completion rates

Questions were not compulsory. While all participants were encouraged to answer all the questions in the Survey, they had a choice about whether to skip a particular question (without prejudice in terms of ongoing participation in the survey, or the *Growing Up in New Zealand* cohort overall).

Question completion rates for the Survey varied between 1.6% and 96.1%. Degree of missing data for

each question are shown in Table 2. It is important to use the information about missingness in conjunction with the study questionnaire, as some missingness is due to question routing, and therefore not all participants were expected to fully complete all questions.

Table 2: Degree of missing data for each question

Question number	Missing data
1	N/A
2	N/A
3-4	See section 4.2
4	n = 94 (3.9%)
5	Item 1: n = 105 (4.3%) Item 2: n = 113 (4.7%)
6	n = 103 (4.3%)
7	n = 2176 (89.9%)
8	n = 2173 (89.8%)
9	N/A
10	Item 1: n = 141 (5.8%) Item 2: n = 168 (6.9%) Item 3: n = 305 (12.6%) Item 4: n = 1101 (45.5%) Item 5: n = 1777 (73.4%) Item 6: n = 2094 (86.5%) Item 7: n = 2228 (92%) Item 8: n = 2310 (95.4%) Item 9: n = 2359 (97.4%) Item 10: n = 2381 (98.3%)
11	Item 1: n = 161 (6.7%) Item 2: n = 192 (7.9%) Item 3: n = 324 (13.4%) Item 4: n = 1111 (45.9%) Item 5: n = 1783 (73.6%) Item 6: n = 2097 (86.6%) Item 7: n = 2229 (92.1%) Item 8: n = 2312 (95.5%) Item 9: n = 2361 (97.5%) Item 10: n = 2382 (98.4%)
12	Item 1: n = 141 (5.8%)

Question number	Missing data
	Item 2: n = 168 (6.9%) Item 3: n = 305 (12.6%) Item 4: n = 1116 (46.1%) Item 5: n = 1777 (73.4%) Item 6: n = 2094 (86.5%) Item 7: n = 2228 (92%) Item 8: n = 2310 (95.4%) Item 9: n = 2359 (97.4%) Item 10: n = 2381 (98.3%)
13	Item 1: n = 141 (5.8%) Item 2: n = 168 (6.9%) Item 3: n = 305 (12.6%) Item 4: n = 1170 (48.3%) Item 5: n = 1777 (73.4%) Item 6: n = 2094 (86.5%) Item 7: n = 2228 (92%) Item 8: n = 2310 (95.4%) Item 9: n = 2359 (97.4%) Item 10: n = 2381 (98.3%)
14	Item 1: n = 141 (5.8%) Item 2: n = 168 (6.9%) Item 3: n = 305 (12.6%) Item 4: n = 1154 (47.7%) Item 5: n = 1777 (73.4%) Item 6: n = 2094 (86.5%) Item 7: n = 2228 (92%) Item 8: n = 2310 (95.4%) Item 9: n = 2359 (97.4%) Item 10: n = 2381 (98.3%)
15	Item 1: n=154 (6.4%) Item 2: n=161 (6.7%) Item 3: n=163 (6.7%) Item 4: n=169 (7.0%) Item 5: n=167 (6.9%) Item 6: n=166 (6.9%) Item 7: n = 168 (6.9%)

Question number	Missing data
16	n=153 (6.3%)
17	Item 1: n = 168 (6.9%) Item 2: n = 173 (7.1%) Item 3: n = 175 (7.2%) Item 4: n = 180 (7.4%)
18	n=162 (6.7%)
19	Item 1: n = 246 (10.2%) Item 2: n = 251 (10.4%) Item 3: n = 251 (10.4%) Item 4: n = 260 (10.7%) Item 5: n = 263 (10.9%) Item 6: n = 263 (10.9%) Item 7: n = 266 (11%) Item 8: n = 267 (11%)
20	Item 1: n = 2346 (96.9%) Item 2: n = 2346 (96.9%) Item 3: n = 2345 (96.9%) Item 4: n = 2345 (96.9%) Item 5: n = 2346 (96.9%) Item 6: n = 2345 (96.9%) Item 7: n = 2345 (96.9%) Item 8: n = 2345 (96.9%)
21	n = 164 (6.8%)
22-35	See section 4.3
36	Item 1: n = 196 (8.1%) Item 2: n = 195 (8.1%) Item 3: n = 197 (8.1%) Item 4: n = 197 (8.1%) Item 5: n = 196 (8.1%) Item 6: n = 200 (8.3%) Item 7: n = 196 (8.1%) Item 8: n = 202 (8.3%) Item 9: n = 197 (8.1%) Item 10: n = 195 (8.1%)
37	Item 1: n = 209 (8.6%) Item 2: n = 209 (8.6%) Item 3: n = 213 (8.8%) Item 4: n = 209 (8.6%) Item 5: n = 210 (8.7%)

Question number	Missing data
	Item 6: n = 210 (8.7%) Item 7: n = 213 (8.8%) Item 8: n = 212 (8.8%) Item 9: n = 213 (8.8%) Item 10: n = 218 (9%)
38	Item 1: n = 209 (8.6%) Item 2: n = 212 (8.8%) Item 3: n = 218 (9%) Item 4: n = 213 (8.8%) Item 5: n = 215 (8.9%) Item 6: n = 213 (8.8%) Item 7: n = 214 (8.8%) Item 8: n = 217 (9%) Item 9: n = 214 (8.8%) Item 10: n = 217 (9%)
39	Item 1: n = 214 (8.8%) Item 2: n = 221 (9.1%) Item 3: n = 222 (9.2%) Item 4: n = 220 (9.1%) Item 5: n = 220 (9.1%) Item 6: n = 219 (9%) Item 7: n = 219 (9%) Item 8: n = 223 (9.2%)
40	n = 267 (11%)
41	n = 297 (12.3%)
42	n = 235 (9.7%)
43	n = 259 (10.7%)
44	n = 322 (13.3%)
45	n = 235 (9.7%)
46	n = 664 (27.4%)

3.2 Baseline demographics

Examples of some demographic variables for the COVID Wellbeing Survey are presented in Table 3 and Table 4, with these variables linked from previous *Growing Up in New Zealand* DCWs. The variables available for linkage can be seen in the data dictionaries for previous DCWs.

Almost all (99%) children participating in the survey were aged 10-11 years. A lower response rate to the survey was observed for boys, Māori, Pacific, and Asian children, and children who had mothers with fewer educational qualifications, though in some cases these differences were modest (e.g., by gender). Response rates did not differ significantly between children living in rural and urban areas.

Ethnicity data can be utilised as 'prioritised' ethnicity and 'total response' ethnicity.

- **Externally prioritised ethnicity** is based on Statistics New Zealand Level 1 ethnicity groupings, in the following order of priority: Māori, Pacific, Asia, Middle Eastern/Latin American/African, Other, or European if used as an independent variable.¹¹ The strengths of this method include prioritisation of the Māori ethnic group, befitting for targeted resourcing and policy development included in Te Tiriti o Waitangi Treaty responsibilities.¹² Additionally, ethnic groupings are mutually exclusive which is a requirement for many statistical tests.
- For **total response ethnicity** is based on Stats NZ Level 1 ethnicity groupings, with multi-ethnic participants included in each relevant ethnic group. The strength of this method is the inclusion of all ethnic groups with which each individual identifies.
- Of the Pacific group (total response), the following nations were represented:
 - Samoan: 53% (n=169)
 - Tongan: 26% (n=83)
 - Cook Island Māori: 22% (n=71)
 - Niuean: 12% (n=38)
 - Fijian: 6% (n=18)
 - Other: <1% (n=<10)
- Of the Asian group (total response), the following nations were represented:
 - Chinese: 30% (n=102)
 - Indian: 29% (n=99)
 - Filipino: 10% (n=33)
 - Other: 34% (n=116)

The 'Other' category represents nations with less than 10% of children from each nation (e.g., Sri Lankan, Korean, Japanese, Cambodian, Vietnamese, etc).

Table 3: Survey response rate by demographic characteristics of the children

	Eligible cohort	Participated in survey	Response rate	Logistic model	
	N	n	%	OddsRatio	P-value
Total	5756	2421	42.1	-	-
AGE[#]					
< 10 years	<10	<10	<1	-	-
10-11 years	5540	2397	99.0	-	-
11-12 years	200	23	<1	-	-
Missing	9	0	0	-	-
SEX[*]					
Boy	2964	1200	40.5	1	Ref
Girl	2784	1220	43.8	1.15	0.024
Missing	8	1	12.5	-	-
ETHNICITY^{**} (externally prioritised)					
European	2599	1339	51.5	1	Ref
Māori	1390	498	35.8	0.76	<0.001
Pacific	738	213	28.9	0.70	0.002
Asian	867	315	36.3	0.69	<0.001
Other	131	55	42.0	0.98	0.917
Missing	31	1	3.2	-	-
ETHNICITY^{**} (total response)					
European	4303	2017	46.9		
Māori	1390	498	35.8		
Pacific	1089	317	29.1		
Asian	979	343	35		
Other	170	64	37.6		
Missing	31	< 10	3.2		

Calculated using the birthdate provided at DCW1, and the date each child participated in the COVID Wellbeing Survey.

* Based on data collected at 6-weeks, participants were grouped into boy or girl as assigned at birth.

** As reported by the mother at the 54-month DCW, with one or more ethnicities permitted. Missing values of ethnicity at the 54-month DCW were replaced with the child's ethnicity reported by the mother at the 9-month DCW.

Table 4: Survey response rate by deprivation, rurality and mother's characteristics

	Eligible cohort	Participated in survey	Response rate	Logistic model	
	N	n	%	Odds Ratio	P-value
Total	5756	2421	42.1	-	-
SOCIOECONOMIC STATUS #					
Low area of deprivation (1-3)	1800	919	51.1	1	Ref
Medium area of deprivation (4-7)	1899	890	46.9	1.01	0.939
High area of deprivation (8-10)	1345	517	38.4	1.01	0.950
Missing	712	95	13.3	-	-
RURALITY *					
Urban	4445	2058	46.3	1	Ref
Rural	599	268	44.7	0.828	0.047
Missing	712	95	13.3	-	-
MOTHER AGE **					
≤ 30 years	159	34	21.4	1	Ref
31 - 35 years	700	188	26.9	1.34	0.226
36 - 40 years	1298	459	35.4	1.56	0.061
41 - 45 years	1873	891	47.6	1.94	0.005
46 - 50 years	1381	685	49.6	2.12	0.002
> 50 years	343	163	47.5	1.94	0.01
Missing	<10	<10	50.0	-	-
MOTHER EDUCATION ***					
No secondary school qualification	319	95	29.8	1	Ref
Secondary school/ NCEA 1-4	1277	423	33.1	1.03	0.85
Diploma/Trade Cert/ NCEA 5-6	1762	632	35.9	1.11	0.518
Bachelor's degree	1419	717	50.5	1.69	0.002

Based on NZDep2013 from the 8-year DCW. NZDep2013 uses 2013 Aotearoa New Zealand census data to derive an indicator of socioeconomic hardship based on selected dimensions of neighbourhood deprivation.¹³ Deprivation scores are categorised into 10 deciles, with decile 1 representing the 10% of neighbourhoods that are the least deprived, and 10 the most deprived.

* Calculated using the residential address from the 8-year DCW for mothers (coded using the 2013 set of meshblock boundaries defined by Statistics NZ).

** Calculated using the mother's date of birth (as reported at the antenatal DCW), and the date each child participated in the the COVID Wellbeing Survey (as per the date stamp within the online survey).

*** Calculated using the mother's report of their education level at the Antenatal DCW. NCEA = National Certificate of Educational Achievement.

4. Utility and benefits

Information collected directly from an existing child cohort has national and international utility for informing strategies to help support the wellbeing of New Zealand children, and children globally, during the time of the COVID-19 pandemic. This was a unique and time sensitive opportunity to gather information from an existing child cohort to inform policy regarding the impact of COVID-19 (and associated government restrictions) on the health, wellbeing and connectivity of young children and their families.

The digital engagement process with the existing cohort of children (who were aged 10-11 years) occurred at a time when they are increasingly undertaking routine daily activities (such as connecting with peers and schoolwork) via digital devices. The application of a digital survey between routine DCWs provided valuable information about the utility and acceptability, as well as the coverage, of this type of engagement with the cohort. The digital survey also provided important information about retention and attrition bias using a digital platform, which has informed contingency planning around an electronic 12-year DCW if COVID-19 continues to restrict face-to-face engagement with the cohort. The digital survey also provided indicative information with regards to digital inequity that can be further explored.

Data from the COVID-19 Wellbeing Survey can be linked to existing measurements collected between birth and eight years, enabling longitudinal comparison of measures over time without any recall bias. The information will also provide intermediate measures for the children on the impact of COVID-19 (and associated government restrictions), that can be re-measured at the upcoming 12-year DCW to identify the longer-term impact of the pandemic on children.

This information can also be calibrated according to the known diversity of young children growing up in New Zealand today. Longitudinal information to understand the immediate impact of COVID-19, what has been protective and what has been most challenging for families with young children, will provide rapid information to inform ways to best support the wellbeing of children during what is likely to be a prolonged period of isolation and changed activity and connectivity.

5. Limitations of the data

This bespoke survey was designed as an interim survey to collect acute measures during a time of high COVID Alert Levels. The information gathered will have greater utility once the 12 year DCW information is available.

5.1 Different data collection process to previous DCWs

As previously mentioned, the COVID Wellbeing Survey utilised an online data collection process. The majority of previous DCWs in the *Growing Up in New Zealand* cohort have involved face-to-face interviews. This difference in data collection methods should be considered when comparing data from the COVID Wellbeing Survey to data from previous DCWs.

5.2 Response bias

Almost two thirds of the *Growing Up in New Zealand* cohort did not participate in the COVID Wellbeing Survey. As an opportunistic survey, it was not expected that all children in the cohort would be reached, so it was anticipated that the sample may not be representative of the full cohort and Aotearoa New Zealand children in general. All users of the dataset will therefore need to take this non-response bias into consideration in any cross-sectional or longitudinal analyses.

Survey response bias was evident by gender, ethnicity, deprivation levels, and mother's age and education, meaning specific findings related to these subgroups may not be representative of the full cohort. The survey strongly reflects the views of girls, European children and children who had older (> 40 years) and more educated mothers (i.e., $\geq$ Bachelor's degree), given the higher participation rate of these groups in the survey.

Item non-response is also an issue to consider in utilizing the data from the survey, given it was not compulsory to answer survey questions.

5.3 Reporting bias

All data in the COVID Wellbeing Survey are self-reported and therefore subject to some degree of bias. For example, more objective measures of activity involvement, screen and media use, and household dynamics may not align with the self-reported measures. Furthermore, some questions may be impacted by social desirability bias. However, as this survey sought to understand the experiences of children during the COVID-19 lockdown, the best way to collect this data was from the children themselves. Consequently, self-report measures were deemed the most appropriate tool for this survey.

5.4 Question comparison with previous DCWs

If comparing measures from the COVID Wellbeing Survey to the same measures in previous DCWs be careful to check the wording, as some questions were phrased slightly differently. Furthermore, be aware that the same measures from different time points may have been completed by different participants.

For example, they may be 'mother reported' in the 8-year DCW compared with 'child reported' with the COVID Wellbeing Survey.

5.5 Age

At least 22 responses related to age (Questions 3-4 in the survey) are incorrect, with some children giving a year or an age that is not possible for children in this cohort (e.g., 2020 or age 43). Consequently, age should be calculated using the birthdate provided at DCW1, and the date each child participated in the COVID Wellbeing Survey.

5.6 Activity participation

At both the 8-year DCW and lockdown, activities (e.g., reading, outdoor sporting activity, and chores) that the children participated in with their family were recorded and can be compared across DCWs (Question 38 in the survey). However, comparisons between activity participation during the lockdown and 8-year DCWs need to be conducted with caution as the 8-year data was reported by the mother whereas the lockdown data was reported by the child. Perceptions of activity engagement may differ across informants.

5.7 Media use and screen time questions

Due to technical errors with the survey linkage, some of the media use questions (Questions 22-35 in the survey) have 97% missing data. This missingness was associated with incorrect skip logic that was reversed for the first question which asked if children had internet access at home. Those who answered 'yes' were routed to the next section, whereas those who answered 'no' received all media use questions. Due to the large amount of missing data this set of questions has almost no utility.

Questions relating to screen time (Questions 27-35 in the survey) remain and have been developed in-house. Some questions (for example, questions about time spent on devices) are the same or like those asked at the 8Y DCW.

5.8 Depression scale

The CES-D 10 data are only available for those children who responded to all items in the scale. However, it may be possible to impute the missed items for those who had <40% missingness across the 10 items (i.e., 51 children would be eligible for imputation).

The CES-D 10 instrument (and the score cut-off of ≥ 10) has not been validated in children aged 10-11 years, although it has been validated in youth aged 13-17 years.¹⁴⁻¹⁶ The depression score is also not reliable for the COVID Wellbeing Survey cohort, although it is for the 8-year DCW. For these reasons, findings from the depression analyses are suggestive-only and require validation.

5.9 Anxiety scale

The PROMIS data are only available for those children who responded to all items in the scale. However, it may be possible to impute the missed items for those who had <40% missingness across the eight items (i.e., 29 children would be eligible for imputation).

The instrument used to measure anxiety has not been validated in an Aotearoa New Zealand population, and the score cut-offs have not been validated in children aged 10-11 years. For these reasons, any findings from the anxiety analyses are suggestive-only and require validation.

5.10 School satisfaction instrument

Data are only available for those children who responded to all items in the scale. The instrument used to measure school satisfaction has not been validated in children aged 10-11 years within an Aotearoa New Zealand sample. Preliminary testing of the instrument suggested the scale has good reliability (as indicated by a high Cronbach alpha value of 0.9). However, further invariance testing and validation of the tool is needed to ensure the validity of this instrument for this population.

6. Growing Up in New Zealand reference publications

It is expected that all researchers interested in using the *Growing Up in New Zealand* datasets will be familiar with the key background documents describing the study in more detail (available at www.growingup.co.nz). In particular:

- **Growing Up in New Zealand Cohort profile**

This journal article describes in detail the cohort design and set up of the study. It is the foundational document for referencing the study.

Morton, S. M. B., Atatoa Carr, P., Grant, C. C., Robinson, E. M., Bandara, D. K., Bird, A., Ivory, V. C., Kingi, T.K., Liang, R., Marks, E. J., Perese, L. M., Peterson, E. R., Pryor, J. E., Reese, E., Schmidt, J. M., Waldie, K. E., Wall, C. (2012). *Cohort Profile: Growing Up in New Zealand*. International Journal of Epidemiology 42(1): 65-75. DOI: 10.1093/ije/dyr206

- **Report 1: Before we are born**

This is the first report released and focuses solely on the antenatal data as well as describing the cohort and research objectives of the study.

Morton, S. M. B., Atatoa Carr, P. E., Bandara, D. K., Grant, C. C., Ivory, V. C., Kingi, T. R., Liang, R., Perese, L.M., Peterson, E., Pryor, J. E., Reese, E., Robinson, E. M., Schmidt, J. M., Waldie, K. E. (2010). *Growing Up in New Zealand: A longitudinal study of New Zealand children and their families. Report 1: Before We Are Born*. Auckland, Growing Up in New Zealand. ISBN: 978-0-473-17889-5 (electronic), ISBN: 978-0-473-17974-8 (print).

- **Report 2: Now we are born**

This report describes the cross-sectional data from the first nine months of our cohort children's lives and the longitudinal changes from antenatal to nine months.

Morton, S. M. B., Atatoa Carr, P., Grant, C. C., Lee, A., Bandara, D. K., Mohal, J., Kinloch, J., Schmidt, J., Hedges, M., Ivory, V., Kingi, T. K., Liang, R., Perese, L., Peterson, E., Pryor, J., Reese, E., Robinson, E., Waldie, K., Wall, C. (2012). *Growing Up in New Zealand: A longitudinal study of New Zealand children and their families. Report 2: Now We Are Born*. Auckland, University of Auckland. ISSN: 2253-251X (Online), ISSN: 2253-2501 (Print)

- **Growing Up in New Zealand recruitment and retention paper**

This paper lays out the methods and techniques used to recruit the largest cohort of participants in a longitudinal study ever undertaken in Aotearoa New Zealand. It also discusses the retention methods used in the study and success rates over time.

Morton, S. M. B., Atatoa Carr, P., Grant, C. C., Robinson, E. R., Bird, A. and Waayer, D. (2012). *How*

do you recruit and retain a pre-birth cohort? Lessons learnt from Growing Up in New Zealand. Evaluation and the Health Professions. DOI: 10.1177/0163278712462717.

- **Alignment of cohort with Population of Interest (all current births)**

The comparability of *Growing Up in New Zealand* births to all the births across Aotearoa New Zealand has also been compared and contrasted.

Morton, S. M. B., Ramke, J., Kinloch, J., Grant, C. C., Atatoa Carr, P., Leeson, H., Lee, A. C. and Robinson, E. (2014). *Growing Up in New Zealand cohort alignment with all New Zealand births*. Australian and New Zealand Journal of Public Health. DOI: 10.1111/1753-6405.12220

- **Report 3: Now We Are Two: Describing our first 1000 days**

This report provides insight into the physical health and development, emotional and behavioural well-being, and cognitive development of Aotearoa New Zealand two-year-olds. The report also depicts changes in the children's home environment, childcare arrangements and socioeconomic situation over the first two years of their lives.

Morton, S.M.B., Atatoa Carr, P.E., Grant, C.C., Berry, S.D., Bandara, D.K., Mohal, J., Tricker, P. J., Ivory, V.C., Kingi, T.R., Liang, R., Perese, L.M., Peterson, E., Pryor, J.E., Reese, E., Waldie, K.E. and Wall, C.R. (2014). *Growing Up in New Zealand: A longitudinal study of New Zealand children and their families. Now we are Two: Describing our first 1000 days*. Auckland: *Growing Up in New Zealand*. ISSN: 2253-251X (Online), ISSN: 2253-2501 (Print)

- **Report 4: Vulnerability Report 1: Exploring the Definition of Vulnerability for Children in their First 1000 Days**

This report evaluates how commonly Aotearoa New Zealand children experience twelve family and environmental risk factors that have previously been shown to increase the chances that children will have poor developmental outcomes.

Morton, S. M. B., Atatoa Carr, P. E., Grant, C. C., Berry, S. D., Marks, E. J., Chen, X. M-H., Lee, A. C. 2014. *Growing Up in New Zealand: A longitudinal study of New Zealand children and their families. Vulnerability Report 1: Exploring the Definition of Vulnerability for Children in their First 1000 Days*. Auckland: *Growing Up in New Zealand*. ISSN: 2253-251X (Online), ISSN: 2253-2501 (Print).

- **Report 5. *Growing Up in New Zealand*: Residential Mobility Report 1: Moving house in the first 1000 days**

This report focusses on the residential mobility of the cohort families during the first two years of their children's lives.

Morton, S. M. B., Atatoa Carr, P. E., Berry, S. D., Grant, C. C., Bandara, D.K., Mohal, J., Tricker, P. J. 2014. *Growing Up in New Zealand: A longitudinal study of New Zealand children and their families. Residential Mobility Report 1: Moving house in the first 1000 days*. Auckland: *Growing Up in New Zealand*. ISSN: 2253-251X (Online), ISSN: 2253-2501 (Print)

- **Report 6. *Growing Up in New Zealand: Vulnerability Report 2: Transitions in exposure to vulnerability in the first 1000 days of life***

This report on vulnerability is based on the information gathered in the first thousand days of the *Growing Up in New Zealand* longitudinal study. This is the second in an evolving series of reports on vulnerability and resilience.

Morton, S. M. B., Atatoa Carr, P. E., Grant, C. C., Berry, S. D., Mohal, J., Pillai, A. 2015. *Growing Up in New Zealand: A longitudinal study of New Zealand children and their families. Vulnerability Report 2: Transitions in exposure to vulnerability in the first 1000 days of life. Auckland: Growing Up in New Zealand.* ISSN: 2253-251X (Online), ISSN: 2253-2501 (Print)

- **Report 7. *Growing Up in New Zealand: Now We Are Four: Describing the preschool years***

This report continues the “Now We Are” series of reports, building on the findings from the “Before We Are Born”, “Now We Are Born” and “Now We Are Two” reports. The information in this report draws on a number of DCWs which capture key transitions for the children between the ages of two and four years. Importantly, it provides a view of how the current generation of preschool children is faring as they prepare to enter formal schooling.

Morton, S.M.B, Grant, C.C., Berry, S.D., Walker, C.G., Corkin, M., Ly, K., de Castro, T.G., Atatoa Carr, P.E., Bandara, D.K., Mohal, J., Bird, A., Underwood, L., Fa'alili-Fidow, J., 2017. *Growing Up in New Zealand: A longitudinal study of New Zealand children and their families. Now We Are Four: Describing the preschool years. Auckland: Growing Up in New Zealand.* ISSN: 2253-251X (Online), ISSN: 2253-2501 (Print)

- **Report 8. *Growing Up in New Zealand: Transition to school***

This report is based on the first six years of the children's lives, and covers their parents and the households and neighbourhoods in which they are growing up.

Morton, S.M.B., Grant, C.C., Walker, C.G., Berry, S.D., Meissel, K., Ly, K., Marks, E.J., Underwood, L., Fa'alili-Fidow, J., Wilson, S., Pillai, A., Kim, H. 2018. *Growing Up in New Zealand: A longitudinal study of New Zealand children and their families. Transition to school. Auckland: Growing Up in New Zealand.* ISSN: 2253- 251X (Online), ISSN: 2253-2501 (Print)

- **Report 9. *Now We Are Eight: Life in middle childhood***

This report continues the “Now We Are” series of reports, building on the findings from the “Before We Are Born”, “Now We Are Born”, “Now We Are Two” and “Now We Are Four” reports. The information in this report primarily describes findings from the information collected at the eight year data collection wave. It also provides a section which aligns the findings with the Child and Youth Wellbeing Framework.

Morton, S.M.B., Walker, C.G., Gerritsen, S., Smith, A., Cha, J., Bird, A., Bullen, P., Atatoa Carr, P.,

Chen, R., Exeter, D.J., Fa'alili-Fidow, J., Fenaughty, J., Grant, C. Kim, H., Kingi, T.K., Lai, H., Langridge, F., Marks, E.J., Meissel, K., Napier, C., Paine, S., Peterson, E.R., Pillai, A., Reese, E., Underwood, L., Waldie, K.E, Wall, C. 2020 . *Growing Up in New Zealand: A longitudinal study of New Zealand children and their families*. Now We Are Eight: Life in middle childhood. Auckland: *Growing Up in New Zealand*. ISSN: 2253-251X (Online), ISSN:2253-2501.

- **Report 10. Life during Lockdown: Finding from the *Growing Up in New Zealand* COVID Wellbeing Survey. Part 1: Health and Wellbeing.**

This report is based on the health and wellbeing outcomes from the COVID Wellbeing Survey.

Walker N, Dubey N, Bergquist M, Janicot S, Swinburn B, Napier C, Peterson E, Evans R, Gerritsen S, Langridge F, Meissel K, Paine S-J, Pillai, A, Bullen P, Waldie K, Smith A, Wall C, Morton S. The Growing Up in New Zealand COVID-19 Wellbeing Survey: Part 1: Health and Wellbeing. Auckland: Growing Up in New Zealand, 2021. ISSN: 2253-251X (Online), ISSN:2253-2501.

- **Report 11. Life during Lockdown: Finding from the *Growing Up in New Zealand* COVID Wellbeing Survey. Part 2: Education.**

This report is based on the educational outcomes from the COVID Wellbeing Survey.

Meissel K, Bergquist M, Kumarich J, Napier C, Peterson E, Smith A, Walker N, Bullen P, Dubey N, Fenaughty J, Gerritsen S, Janicot S, Langridge F, Paine S-J, Pillai, A, Swinburn B, Taufa S, Wall C, Morton S. The Growing Up in New Zealand COVID-19 Wellbeing Survey: Part 2: Education. Auckland: Growing Up in New Zealand, 2021. ISSN: 2253-251X (Online), ISSN:2253-2501.

Further *Growing Up in New Zealand* publications which may be of use are available online at (www.growingup.co.nz).

The processes around external data release and technical documents provided align with similar contemporary longitudinal studies overseas, such as:

- Growing Up in Ireland - www.growingup.ie
- Growing Up in Australia - www.growingupinaustralia.gov.au
- Millennium Cohort Study (UK) - www.cls.ioe.ac.uk
- Growing Up in Scotland - <http://growingupinscotland.org.uk>.

7. Preparation of external datasets

Once the field data collection is complete the raw information and observational data are extracted, data is cleaned and collated, and 'operational only' data are removed. The raw research data are initially formatted as an internal working dataset. External research datasets are produced according to guidelines that protect participant privacy (satisfying safe data in the international Five Safes framework) and in compliance with participant consent for data use.

External Research Datasets are datasets made available to bona fide data users for approved research projects in accordance with the *Growing Up in New Zealand Data Access Protocol*. External datasets do not contain identifying information. Identifying Information is defined as personal information (see the Privacy Act 1993) and includes data collected about a person from which the identity of that person or a member of his or her family could reasonably be ascertained.

The data are anonymised without compromising the value of the information for research purposes. In order to protect the anonymity of participants a small proportion of the data are re-coded or re-classified, or in rare cases removed from the external research datasets.

Details regarding the variables available in external datasets are available in the Data Dictionaries for each component of each completed DCW (Table 5).

Table 5: Summary of *Growing Up in New Zealand* external data releases to date (August 2020)

Data Collection Wave	Contact Point	Mother information	Partner information	Child information
DCW ₀	Antenatal	✓	✓	
DCW ₁	Perinatal			✓ *
	6 weeks	✓		✓
	35 weeks	✓		✓
	9 months	✓	✓	✓ **
DCW ₂	16 months	✓		✓
	23 months	✓		✓
	2 years	✓	✓	✓
DCW ₃	31 months	✓		✓
DCW ₄	45 months	✓		✓
DCW ₅	54 months	✓		✓
DCW ₆	72 months	✓		
DCW ₈	8 years	✓		✓

* Derived after linkage to perinatal health records.

** Includes derived variables following linkage to health records in first year of life..

7.1 Data anonymisation

Growing Up in New Zealand adopts and completes the anonymisation process in the context of international best practice and aligned to the Five Safes framework as it is applied to this context (see Data Access Protocol). *Growing Up in New Zealand* does not use any perturbative techniques that reduce and distort original data structures and the distribution of data values.

The anonymisation process removes all direct identifiers and other identifying information that is determined to be highly disclosive (highly sensitive) and with a very high likelihood of breaching the confidentiality and/or privacy of individual participants. Some sensitive or identifiable items are retained where variables are deemed to be useful or important for research purposes and where sensitivity risk and identification risk are judged to be low.

Data has only been removed or transformed/treated if the following criteria were met:

1. Direct participant identifiers;
2. Highly disclosive content; and
3. Categories with cell counts less than five cases of the entire dataset.

The transformation applied to variables is detailed in the Data dictionaries, with treatments defined as raw (unchanged), derived, categorised, or re-classified. Each type of variable transformation is defined as follows:

- **Derived variables:** A new variable that has been generated from one or more raw pieces of information collected, using a numerical computation or mathematical formula or composite score.
- **Categorised variables:** Highly sensitive raw variables with categories containing low cell counts (<5) have been collapsed into the most proximal category (either top or bottom-coding).
- **Re-classified variables:** Variables resulting from multiple response questions exhibiting low cell counts (<5) or mapping low level raw data information to the high-level classification and external standards such as ethnicity or language classifications from Statistics New Zealand.

Note: When we have used the term 'derived' in reference to variables, this definition is interchangeable depending on the context. Some of the variables from DCW0 have been both derived and subsequently top/bottom coded due to extremely low cell counts. For example, a variable for the 'length of time spend living in the current home' was defined as 'derived and categorised' in DCW0P.

Furthermore, the following data items have also been incorporated into the External Working Datasets having been derived from information collected and stored separately from the research data along with the participant nominal information:

- **Geolocation information:** Such as New Zealand Deprivation, District Health Board of domicile and 'urban-rural' location.

- Country of residence: *Growing Up in New Zealand* engages with families and children who move overseas and collects country of residence to conduct interviews. Where a child and/ or their mother are living outside Aotearoa New Zealand the specific country information is collapsed into “Other country” to protect anonymity.

The guiding principles that have been adopted to create the External Working Datasets are summarised in Table 6 below:

Table 6: Data anonymisation principles applied to external datasets

Variable Type	Principle applied
Highly sensitive raw information	Data are presented as derived, categorised or re-classified. These transformed variables still provide the necessary information to undertake analyses
Categorical variables with low cell counts	Low cell count categories have been categorised
Continuous variables with low frequencies at the lower or the upper extremes	Low frequency extremes distributions have been categorised
Multiple-response variables with low frequencies	Responses with low frequencies (≤ 5) have been combined to create a new response variable
Date-specific variables	Dates have been converted to day, month or year
Free text variables	Free text is not released (suppressed). However, if free text has been classified and categorised, then it will be released.
Study unique identifiers (ID)	Data are replaced by pseudo identifiers for external datasets to enable linkages with other currently available <i>Growing Up in New Zealand</i> external datasets

7.2 Additional considerations when planning data analysis

Every effort is made to ensure the quality and accuracy of the *Growing Up in New Zealand* datasets and related documentation. It is however important to acknowledge the evolving complexity of the datasets available, which will increase over time, and the iterative nature of longitudinal datasets. Consequently, before carrying out any analyses it is essential that researchers familiarise themselves with some key issues. These can be broadly described as two types of issue: data preparation and exploratory data analysis.

7.2.1 Data preparation

Coding

- **Reverse coding** – before creating composite scores from the sum or mean of individual variables, check the wording of the item in the questionnaire and it's 'polarity' in comparison with other variables in the composite.
- **Re-coding** - are the values of the variables coded appropriately for your needs?
- **Up-coding** - The majority of our questions are closed in format, thus much of our coding and data checking is done during the interview. However, where there are open ended questions the data have to be reviewed and where relevant coded into separate categorical variables after the interview. Other questions had pre-defined coding frames but "Other – please specify" options were available to the participant which also required post interview up-coding. The newly coded responses for both additional codes and variables appear in the dataset, but all text from the original responses have been removed to protect the respondent's identity.

Examples of reverse and re-coding:

- # In the 9 month Mother dataset, items 1 and 10 of the Edinburgh Postnatal Depression Scale are worded positively while the rest of the items are worded negatively (as is standard for the tool). Values for these variables will need to be reversed before adding the 10 scale items.
- * In the 9 month Mother dataset, the Edinburgh Postnatal Depression Scale items (EDI1_m9M to EDI10_m9M) are coded 1 to 4. However, the original scale is coded 0 to 3. Failure to recode the values would lead to inflated scores.

Missing data

Note data may be missing for a variety of potential reasons:

- **Genuine missing data** – participant did not answer the question, in this case the cell in the dataset will be blank (frequencies of genuine missingness are provided in the Data dictionaries (available at www.growingup.co.nz) and detailed further in the data profiles on the eResearch platform.
- **Refused/ Don't know** – participant refused to answer or gave "Don't know" as a response. Usually these responses are coded 98 or 99 (or in some cases 9). Statistical packages will not automatically recognise that these values indicate missing data.
- **Skipped data/Routing** – these data are missing by design because not all participants are asked to answer all items in a questionnaire. That is, participants might 'skip' items depending on their prior responses (routing applied in the questionnaires). In these cases the cell in the dataset will be blank and responses will appear to be missing.

7.2.2 Exploratory data analysis

Suggested further considerations prior to analysis include:

- Missing data – are there any patterns to the missing data? This includes bias (genuine missing data and Refused/ Don't know data).
- Checking for normality (continuous/scale variables) – can scale data be analysed using parametric tests, and what is the distribution of that data?
- Transforming scale variables into categorical variables – are there known cut-offs that can be used to transform scale data into categories or does the distribution of scores suggest that this would be appropriate?
- Checking the distribution (nominal and ordinal/ categorical variables) – is there such uneven distribution across responses that the variable cannot be meaningfully included in statistical analyses?
- Collapsing categorical variables – would it make sense to collapse nominal or scale data into fewer categories (based on the literature or based on the distribution of responses)?

7.3 Data use disclaimer

While all care and diligence has been used in processing, analysing, and extracting our research data and data dictionaries, we give no warranty it is error free. We recommend that users exercise their own skill and care with respect to their use of the data/ information and carefully evaluate the accuracy, currency, completeness, and relevance of the data for their purposes. All scales and tools have been used/ adapted or developed according to the published literature. For proper usage of these tool/ scales please refer to the pertinent documentation within this guide. Note that improper use of these tools will result in erroneous/ incorrect output.

8. Protecting participant anonymity

8.1 Study principles and participant consent

One of the most important principles of the *Growing Up in New Zealand* study is that the data made available are anonymised. This protects the privacy of participants and enables the collection of sensitive data because confidentiality is assured.

The consent form for participants stated:

“I understand that the research team will keep my involvement in this study confidential, and that no material that could identify me will be used in any reports on this study.”

The Participant Information Sheet that accompanied this Consent Form stated:

“The information about your child and family is completely confidential. No information that could identify you or your child will be used in any reports on this study.”

In all processes, *Growing Up in New Zealand* must therefore ensure that all researchers adhere to these statements and keeping data anonymous must be balanced with providing data for robust, contemporary, population relevant analyses. For this reason, the use of all external datasets must ensure that:

- Involvement in the study is kept confidential and individual participants cannot be identified;
- All access to the *Growing Up in New Zealand* data is driven by the requirements set out in the *Growing Up in New Zealand* Data Access Protocol; and
- All access to the *Growing Up in New Zealand* data is overseen by the Data Access Committee.

8.2 The 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 accessed. All researchers using the *Growing Up in New Zealand* external datasets must be familiar with the Data Access Protocol which is available on the study website (www.growingup.co.nz).

The Data Access Protocol includes:

- The principles that govern data access.
- The process by which researchers may apply for data access.
- The provisions that are used to safeguard the privacy of study participants and their families.
- The provisions that are used to ensure the long-term sustainability of the study.

- The role and function of the Data Access Committee that will oversee the operation of the protocol.
- All publications that utilise the data must be approved by the Data Access Committee prior to being submitted for publication. This is to ensure that the publication is in keeping with the principles of confidentiality and sustainability laid out in the Data Access Protocol.

As part of this Data Access Protocol, applications to use the external working datasets must include a brief dissemination plan. Further information about how to apply for the external working datasets is available at www.growingup.co.nz.

8.3 The Data Access Committee

The role of the *Growing Up in New Zealand* 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 working datasets cannot be used without the prior approval of the Data Access Committee and adherence to the Data Access Protocol.

8.4 Data security requirements

The Researcher will not, directly or indirectly, disclose or permit to be disclosed to any person the Dataset and/ or any results obtained from use of the Dataset except in accordance with the Dissemination Plan.

The Researcher will have and maintain security arrangements to safeguard the Dataset from unauthorised access that adhere to industry-accepted "best practices" for information of the same level of sensitivity. The Researcher will ensure that access to the Dataset is limited to them under this Agreement to access the Dataset. Only the Researcher(s) listed in this agreement is permitted to access the Dataset.

9. References

1. Ministry of Health. COVID-19: Case demographics. Ministry of Health, Wellington.
<https://www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus/covid-19-data-and-statistics/covid-19-case-demographics>
2. Ministry of Health. COVID-19: Current Cases. Ministry of Health, Wellington.
<https://www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus/covid-19-data-and-statistics/covid-19-current-cases>
3. Bradley KL, Bagnell AL, Brannen CL. Factorial Validity of the Center for Epidemiological Studies Depression 10 in Adolescents. *Issues in Mental Health Nursing*. 2010 May 7;31(6):408–12
4. DeWalt DA, Gross HE, Gipson DS, et al. PROMIS pediatric self-report scales distinguish subgroups of children within and across six common pediatric chronic health conditions. *Quality of Life Research*. 2015;24(9):2195–208.
5. Northwestern University. PROMIS Reference Populations. 2020 Jul 10. p. 1–7.
6. Liebenberg L, Ungar M, Vijver FV. Validation of the child and youth resilience measure-28 (CYRM-28) among Canadian youth. *Research on social work practice*. 2012;22(2):219–26.
7. Huebner ES, Gilman R. An Introduction to the Multidimensional Students' Life Satisfaction Scale. *Social Indicators Research*. 2002;60(1):115–22.
8. Rowe EW, Kim S, Baker JA, Kamphaus RW, Horne AM. Student personal perception of classroom climate: Exploratory and confirmatory factor analyses. *Educational and Psychological Measurement*. 2010;70(5):858–79.
9. Irwin DE, Stucky B, Langer MM, et al. An item response analysis of the pediatric PROMIS anxiety and depressive symptoms scales. *Quality of Life Research*. 2010 May 7;19(4):595–607.
10. PROMIS Score Cut Points. Northwestern University. Available from:
<https://www.healthmeasures.net/score-and-interpret/interpret-scores/promis/promis-score-cut-points>
11. Statistics New Zealand. Ethnicity standard classification: Findings from public consultation November 2019. Statistics New Zealand, Wellington: 2020. Available from www.stats.govt.nz.
12. Callister P, Didham R, Potter D, Blakely T. Measuring ethnicity in New Zealand: developing tools for health outcomes analysis. *Ethnicity and Health*. 2007;12(4):299–320.
13. Salmond CE, Crampton P. Development of New Zealand's deprivation index (NZDep) and its uptake as a national policy tool. *Canadian Journal of Public Health/Revue Canadienne de sante'e publique*. 2012;7-11.

14. Bradley KL, Bagnell AL, Brannen CL. Factorial Validity of the Center for Epidemiological Studies Depression 10 in Adolescents. *Issues in Mental Health Nursing*, 2010; 31:6, 408-412.
15. Cartierre N, Coulon N, Demerval R. Analyse confirmatoire de la version courte de la Center for epidemiological studies of depression scale (CES-D10) chez les adolescents. *L'Encephale*. 2011; 37: 273–277.
16. Kilburn, K., Prencipe, L., Hjelm, L. *et al.* Examination of performance of the Center for Epidemiologic Studies Depression Scale Short Form 10 among African youth in poor, rural households. *BMC Psychiatry* 2018; 18, 201.