

# Why New Zealand needs a policy on Longitudinal Birth Cohort Studies

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*Addressing key needs to enhance the value*

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## Executive Summary

*“Longitudinal cohort studies are the only mechanism for studying processes, developments, and dynamics of an individual life course, and enable investigating the effects of earlier characteristics on later outcomes”.<sup>1</sup>*

## Introduction

Longitudinal studies provide a valuable resource for the academic community, researchers, healthcare practitioners, and policy decision makers. These studies are critical to build our understanding of how biological, social, environmental, and any other factors interact over time in a population to produce individual and societal health and wellbeing outcomes.<sup>2,3</sup>

An enduring, long-term study is invaluable in enabling data comparisons over several decades, and the study of inter-generational mobility of socio-economic, demographic, genetic and other factors. A new longitudinal birth study cohort set up approximately every decade enables health practitioners, communities, and key decision makers to address the issues and determinants relevant to each next generation. This has never been more relevant than the present, especially given the rapidity of technological and secular change witnessed over the last several decades.

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<sup>1</sup> Strategic review of panel and cohort studies. Report to the Research Resources Board of the Economic and Social Research Council. 2006.

<sup>2</sup> The case for a new Australian birth cohort study. Institute for Social Science Research. 2014.

<sup>3</sup> Longitudinal Studies and the National Centre for Longitudinal Data Overview Guide. Australian Government Department of Social Services. 2016.

## Purpose

This paper provides an overview of the current landscape of longitudinal birth cohorts (hereafter longitudinal cohorts) in New Zealand. It also includes an overview of select few international examples that have set up, developed and maintained a successful continuum of a national longitudinal cohorts infrastructure. The purpose of this paper is to make the case for a system of longitudinal cohorts to be established as a key part of New Zealand's national RSI infrastructure. This system needs to be supported by long-term sustainable funding; to have responsibility for commissioning new cohorts; and have a central, stable, and enduring national governance, kaitiakitanga, and co-design structure. All other type of longitudinal studies (disease cohorts, surveys, etc.) are beyond the scope of this paper.

## Key Recommendations

1. Develop a national policy on longitudinal cohort studies, with mandate for the provision of supporting infrastructure, capability in key host institutions, and standardised processes to establish new cohorts on a regular cycle.
2. Establish long-term, independent funding for continuity of key strategic longitudinal cohorts as part of New Zealand's RSI infrastructure with further funding for sub-studies nested within these cohorts or new cohorts to address a critical current or emerging issue.
3. Establish an enduring central, overarching national governance, kaitiakitanga, and co-design structure to reduce strategic, scientific, and operational duplication; provide academic and political leadership; set up efficient decision-making procedures and consensus building; and to commission new cohorts.

## Background

Longitudinal cohorts deliver an impressive scientific and wider societal yield. They offer time-series data which is generated by following a number of individuals across extended time periods. This enables study of population trends, social impacts, impact of national initiatives such as vaccination programmes, impact of natural disasters, and other unprecedented events on overall wellbeing, mortality, morbidity, disease incidence, quality of life, to name a few. Longitudinal research differs from standard epidemiological research by explicitly using age as a window on (potential) mechanism(s). This gets closer than any other approach to answering the key policy question – *“What, for whom and when?”*<sup>2</sup>

At the most general level, longitudinal cohorts provide a holistic view of life events, exposures, and consequent outcomes which in turn enable a better understanding of aetiological mechanisms that underlie health and wellbeing outcomes. These studies also help identify

individual differences in disease incidence, exploration of social and structural determinants, and monitoring of inequities in physical and mental health.<sup>4</sup>

By providing a deeper, longer, and multi-dimensional view, longitudinal cohorts can inform policies and programmes developed to improve lives. Such studies enable testing and evaluation of the impact of these policies and programmes, and their relevance to “on-the-ground” realities. They provide a continually evolving, robust evidence-base needed for development of effective and targeted interventions, and measure and evaluate the effectiveness of these interventions. Implementation of longitudinal cohorts is also known to increase capacity building as health personnel are trained in research methodologies.<sup>5</sup>

With increasing use of and access to big data, in combination with longitudinal cohort data, heralds a “data revolution”, leading to improved and strengthened data collection systems. Longitudinal data is essential to addressing numerous diverse long-term issues of concern. Greater harmonisation and comparability of data among longitudinal cohorts and other registries will further deepen the understanding of factors influencing health and wellbeing outcomes for key issues such as<sup>1</sup>:

- Ageing population
- Demographic shifts and mobilities and their impact
- Long term effects of childhood exposures and experiences
- Cycles of deprivation
- Disadvantaged populations for whom targeted intervention programmes need to be developed and evaluated
- Intergenerational transfer of resources and its impact on health disparities and inequitable outcomes<sup>6</sup>
- Impact of immigration and globalisation
- Multi-factorial and ever-changing impact of wider determinants on health such as depression and anxiety, inadequate education, economic status, poor housing, climate change, increasing traffic, poor dietary choices, new synthetic chemicals, use of medication
- Emerging and disruptive technology such as synthetic biology, genomics
- New and emerging risk factors
- Current and future probabilities and risks in health and behavioural outcomes

Longitudinal cohorts provide a unique opportunity to find solutions via trends observed over time. For example, they may help determine why one population group is more resilient to certain medical conditions than another. This fosters innovation and supports the

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<sup>4</sup> A systematic review of the effect of retention methods in population-based cohort studies. BMC Public Health. 2011

<sup>5</sup> Strength in Numbers. How longitudinal research can support child development. Global Longitudinal Research Initiative. UNICEF. 2015.

<sup>6</sup> WAI 2575 Māori Health Trends Report. <https://www.health.govt.nz/system/files/documents/publications/wai-2575-maori-health-trends-report-04mar2020.pdf>

development of novel intervention strategies to improve and enable equitable outcomes for specific population groups, or the transfer of insights from one group to the entire population.

The longer a study endures, the greater its value<sup>7</sup> in terms of data comparisons over several waves, and ability to study inter-generational mobility. However, for this to occur, longitudinal cohorts need to be prioritised as a key part of the national RSI infrastructure. They need to be supported by long term, sustainable funding, ability to commission new cohort studies,<sup>8</sup> and structured and stable governance. A committed principal investigator, a highly skilled team of researchers and research support staff are all crucial to providing stable leadership and ongoing quality outputs.

This paper provides an overview of the current landscape of well-established longitudinal cohorts in New Zealand, and a select few international examples we can draw on (Appendix I).

## Objectives

1. To support the development of a national policy on longitudinal cohorts and ensure there is balance between the ongoing benefits and opportunities of well-designed cohort studies, and their significant, long-term costs.
2. To seek the RSI sector's views on the recommendations to build longitudinal cohorts into the RSI infrastructure of New Zealand; how their value could be enhanced to harness the health and socioeconomic benefits for New Zealand; and key enablers to achieving this successfully including funding and governance.

## Scope

For longitudinal cohorts, participants may be recruited from the general population and based on one or more sociodemographic characteristics (ethnicity, gender, geographical location), or from specific patient groups based on pre-determined clinical inclusion and exclusion criteria.

Population cohorts involve healthy individuals and are designed to be able to identify potential causal relationships between multiple outcomes and diverse risk factors. In contrast, disease based prospective studies tend to be narrower in focus and are designed to address clinical questions. While disease-based studies require smaller sample size (at least 100 patients) and shorter follow-up, population cohort studies require a larger sample (at least 1,000 healthy participants) and a long-term, ongoing, follow-up.

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<sup>7</sup> The value and future of birth cohort studies for social science and policy. Summary of Round Table meeting at the British Academy. 2017.

<sup>8</sup> Te Ara Paerangi Future Pathways Green Paper. Ministry of Business, Innovation and Employment. 2021.

This paper focuses on population cohorts (specifically, longitudinal birth cohorts). Review of individual studies, disease cohorts, surveys, panel studies, patient outcomes studies, randomised controlled trials, or any discontinued cohort studies is beyond the scope of this paper.

## Overarching strategic questions that need to be considered

1. What are the challenges/barriers faced in establishing and maintaining longitudinal cohorts as part of the national RSI infrastructure?
2. What is the government's role in longitudinal cohort studies? Is there an opportunity to set up a national guardianship and oversight function?
3. What are the opportunities that can be harnessed to increase the value of longitudinal cohorts?

## Current state of longitudinal cohorts in New Zealand

New Zealand has several long-running longitudinal cohorts such as the Dunedin Multidisciplinary Health and Development Study (the Dunedin study),<sup>9</sup> and the Christchurch Health and Development Study (the Christchurch study).<sup>10</sup> There are two other well-established cohorts of shorter duration: the Pacific Islands Families Study (the PIF study),<sup>11</sup> and the Growing up in New Zealand (GUiNZ) study.<sup>12</sup> These studies have made important contributions to population health insights, to healthcare policies and guidelines, and to healthcare service delivery and practice.<sup>13</sup>

### 1. The Dunedin Multidisciplinary Health and Development Study<sup>9</sup>

Described as an “international treasure” the ongoing Dunedin Multidisciplinary Health and Development Study (the Dunedin Study) was established in 1972. Researchers from University of Otago Medical School started following up 1,037 babies born between 1 April 1972 and 31 March 1973.

The study grew out of a larger study conducted between 1968 and 1973 about perinatal health. The longitudinal cohort comprised 91% of all those born in Dunedin between 1<sup>st</sup> April 1972 and 31<sup>st</sup> March 1973 with the aim of investigating broader questions about child health and

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<sup>9</sup> The Dunedin Multidisciplinary Health and Development Study: overview of the first 40 years, with an eye to the future. *Social Psychiatry and Psychiatric Epidemiology*. 2015.

<sup>10</sup> The Christchurch Health and Development Study: review of findings on child and adolescent mental health. *Australian and New Zealand Journal of Psychiatry*. 2001.

<sup>11</sup> Pacific Islands Families Study. AUT Pacific Health Research Centre. <https://phrc.aut.ac.nz/our-research/pacific-islands-families-study>.

<sup>12</sup> Growing Up in New Zealand cohort alignment with all New Zealand births. *Australian and New Zealand Journal of Public Health*. 2014.

<sup>13</sup> Review of New Zealand Longitudinal Studies. Families commission kōmihana ā whānau. 2005.



development. The study now operates seven major research themes focusing on respiratory health, oral health, neurocognition and mental health, cardiovascular risk, psychosocial functioning, sexual and reproductive health, and maximising the benefits of study's findings for Māori.

The Dunedin study collects data through structured interviews, direct physiological and psychological tests, physical examinations, as well as via data linkages from official data repositories. The data collection waves have been at age 3, 5, 7, 9, 11, 13, 15, 18, 21, 26, 32, 38 and most recently at 45 years when just over 94% of the living study members participated. The study has resulted in several off-shoot sub-studies such as the Family Health History Study (parents' and other family members' mental and physical health), the Parent Study (parenting styles and intergenerational parenting behaviours), and the Children and Parents Study (intergenerational transfer of health problems).<sup>14</sup>

Some significant contributions made by the Dunedin study are:

- Over 880 peer-reviewed scientific publications
- Seminal work addressing nature-nurture interplay and how the combination of both are critical in understanding life outcomes, vulnerability and resilience.
- Papers demonstrating that 80% of the costs to society (eg, use of health services, benefit dependence, time in jail) occurs within 20% of the population, and that the 20% can be reliably identified early in the life course.
- Child Health and Child Health Services report which laid the foundation for a nationwide health and development screening programme for children and was a precursor to the Ministry of Health's Well-Child programme (administered by the Plunket Society and other Well Child Tamariki Ora providers)
- Injury research that was instrumental in ensuring that thermostats were introduced in hot water cylinders
- Contribution to the Amicus brief resulting in overturning the death penalty for those aged under 18 years in the United States of America

## **2. The Christchurch Health and Development Study<sup>10</sup>**

Initially set up as a study to investigate the impact of single parenthood on child health and well-being, the Christchurch study was subsequently scaled to a longitudinal cohort. It has been following 1,265 Christchurch-born children since 1977. The children have been studied from infancy into childhood, adolescence, and adulthood with particular focus on health, education, and life progress.

The Christchurch study collects data through parental interviews, teacher reports, child assessments and interviews. The data collective waves have been at birth and at age 4 months,

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<sup>14</sup> <https://dunedinstudy.otago.ac.nz/>

1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 18, 21, 25, 30, 35 years with the most recent assessment conducted at age 40 when 74% of the living Study members participated.

Some significant contributions made by the Christchurch study are:

- Over 500 peer-reviewed scientific publications
- World-first finding that users of methamphetamine were significantly more likely to be the perpetrators of violence, or be the victim of intimate partner violence, highlighting the need to intervene and reduce rate of methamphetamine abuse within the general population
- Childhood predictors of adult obesity specifically in New Zealand (being male, born into a single-parent family, parents with larger body size, limited or no breastfeeding, higher early infant growth, decreased cognitive ability, exposure to severe sexual abuse)
- Family-based intervention programme – Early Start, which aids, supports, and empowers families in relation to issues around childhood wellbeing and family functioning. Family Support Workers, through this programme, help families to seek necessary treatment, therapy, and advice. This led to improved preschool attendance and performance, health, parenting, child behaviour, reduced child abuse, swimming pool fencing, to name a few.

### **3. Pacific Islands Families Study<sup>11</sup>**

The only Pacific peoples' study in the world, the PIF study was established as a pilot study in 1998. After testing and validating various instruments, recruitment, and interview procedures, the study was scaled into a prospective, longitudinal cohort study. The PIF has been tracking the health and development of 1,398 Pacific children, and their parents, since their birth in the year 2000 at Middlemore Hospital, South Auckland. The data collection waves have been at age 6 weeks, 1, 2, 4, 6, 9, 11, 14, 17, and most recently at 18 years when just over 67% of the foundation cohort members participated.

The PIF study was designed with broad aims of one, identifying risk and resilience factors that influence positive and negative health outcomes during critical developmental periods; and two, to provide Pacific-specific evidence and make strategic recommendations to improve the health and well-being of Pacific children and their families, and address the social disparities they face in New Zealand.

The PIF study collects data through structured interviews with children, mothers, and fathers, and physical health and development assessments. The PIF study also has high retention rates. The data collection waves are from 6 weeks postpartum to when the children are aged 18 years. These data are combined with data from Ministry of Education, Ministry of Health, and other sources to provide a holistic view on the health and development of these Pacific children and their families.

Some significant contributions made by the PIF study are:

- Over 125 peer-reviewed scientific publications
- The adverse impact of food insecurity on child body composition, particularly during early development and its association with higher abdominal and visceral fat in boys
- Impact of problem-gambling among Pacific people and the need for intervention
- The need for targeted education-based intervention in Pacific mothers to ensure exclusive and continued breastfeeding after six weeks and its health benefits for their infants
- Significant proportion of infants sharing beds with their parents, resulting in greater sudden infant deaths in Pacific families.

#### 4. Growing Up in New Zealand<sup>12</sup>

GUiNZ was developed in response to a government call, in 2004, for a contemporary study of New Zealand children and families. Upon successful submission of the study proposal to the Health Research Council of New Zealand, Policy Advisory Group, and international scientific review panel, University of Auckland was awarded the study-development contract. Officially launched in 2008, researchers from the University of Auckland recruited 6,822 pregnant women and 4,401 of their partners from the region covered by Auckland, Counties Manukau and Waikato district health boards, resulting in a broadly generalisable cohort of 6,846 children born between 1 March 2009 and 31 May 2010.

The only longitudinal cohort in New Zealand to recruit prenatally, GUiNZ collects data through interviews, measurements, and activities with mothers, fathers, and children. The data collection waves are from before the children were born (last 12 weeks of pregnancy) and the when the children are at age 6 weeks, 9, 16, 23, 24, 31, 45, 54, 72 months, and most recently at 8 years with 81% of the foundation cohort still participating. The data collection waves are expected to continue to when they are 21 years of age (in 2030). A unique strength of the study is the ethnic diversity of the cohort, with over 1,000 children identifying as Māori at 8 years of age.<sup>15</sup>

The study focuses on six main areas that are fundamental to child development – child health and wellbeing, family and whanau, education, psychological and cognitive development, neighbourhood and environment, and culture and identity.<sup>16</sup>

Some significant contributions made by GUiNZ are:

- Over 185 peer-reviewed scientific publications
- Identifying unmet need for mental health support in pregnant New Zealand women who have significant rates of untreated serious depression, particularly Māori, Pacific, and Asian mothers

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<sup>15</sup> Growing Up in New Zealand: A longitudinal study of New Zealand children and their families. Now We Are Eight. 2021.

<sup>16</sup> <https://www.growingup.co.nz/key-findings-0>

- Finding that private rental homes had significantly fewer safety features such as working smoke alarms. This finding was translated into the New Zealand Residential Tenancies Act regulations 2016 which now mandates working smoke alarms to be present in all rental homes
- Awareness that children exposed to persistent adverse environments (material disadvantage, poverty) experience poorer overall health and wellbeing; are less likely to be immunised; are more likely to be overweight or obese; have more behavioural issues; and are less prepared for formal schooling
- Findings showing that many young children in New Zealand are not eating a diet that is consistent with the nutrition guidelines, which contributed to updated population-health recommendations for feeding children under two years of age to promote healthy eating, growth and development (Healthy Eating Guidelines for New Zealand Babies and Toddlers (0-2 years old)).

## Common Themes

The national (as above) and international (Appendix I) examples of longitudinal cohorts have the following themes in common:

1. The studies were set up or scaled up to meet broad objectives that can be used to study multiple outcomes.
2. Data infrastructure (eg, Integrated Data Infrastructure)<sup>17</sup> with linkages across the study data and various other sources such as police records, medical records, social data is important to provide a comprehensive view of determinants that impact health and wellbeing of populations.
3. Significant investment and effort are needed to maintain these cohorts and participation given the globalisation of today's world and over time, an increasingly dispersed participant cohort.
4. These studies have evolved over time into infrastructure and established skills and knowledge base from which new cohorts/studies can be built upon to deliver relevant and meaningful results with impact on practice, policy, and overall wellbeing of current and future generations. This is despite the logistical efforts and lack of long-term sustainable funding (in New Zealand) required for successful execution and continuity of this invaluable infrastructure.

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<sup>17</sup> <https://www.stats.govt.nz/integrated-data/integrated-data-infrastructure/>

## Value Proposition to New Zealand

A national longitudinal cohort provides unique benefits and is essential to producing comprehensive, cross-cutting data needed to develop sound and priority-informed policies. Such studies will have important health and economic value:

### 1. Health and Healthcare Value

The Ministry of Health and other government agencies (eg, Ministry of Social Development, Oranga Tamariki, Ministry of Education, Ministry of Justice including Police and Corrections) can benefit from knowledge generated by longitudinal cohorts, with key data infrastructure in place, to:

- provide requisite evidence to evaluate and develop new and improve existing policies for general and specific population groups
- seed interventional studies with existing cohorts as controls, or as nested studies within the cohorts
- analyse policy impacts and effects of interventional changes such as changes in health seeking behaviour
- assess potential impacts of policy changes in improving health and wellbeing.

### 2. Economic Value

Longitudinal cohorts foster innovation in various industries, in turn generating economic returns which include:

- Medical technology: advancements in sensor and digital technology (smart phones, wearables, continuous monitoring devices) have led to new possibilities in health management, particularly for chronic disease management such as diabetes. Digital intervention can influence behaviour to improve treatment compliance by, for example, using app-based reminders to track patient compliance (or via new technology such as smart pill) to drugs. Consumer digital health providers/innovators can progress their product development/innovation efforts by accessing well-designed cohorts and linked datasets for direct testing and tracking outcomes real-time and over time.
- Precision-driven health solutions: cohort data may enable development of health interventions to tailor them specifically to individuals much more effectively.
- Data and process innovation: data storage and interpretation are one of the key constraints for large-scale genomic, clinical, and behavioural data solutions. This creates possibilities for process innovation in the growth of industry involved in developing new tools for data processing and interpretation.

Data from these national longitudinal cohorts also help governments save by reducing costs of maintaining policies that do not achieve the intended effects, are inefficient or no longer appropriate.

## Challenges and Opportunities

The value proposition of longitudinal cohorts as a research and community resource is well-recognised overseas. For example, the Wellcome Trust and Medical Research Council of the UK have developed and implemented policies and strategies to maximise the value of cohorts.<sup>18,19</sup> While the Health Research Council of New Zealand outlines the need to develop a new mechanism to support longitudinal cohorts, ensuring continuity of funding and stability for teams building major datasets that are a national and international resource,<sup>20</sup> a dedicated funding stream and secure employment for core staff of current longitudinal cohorts is lacking. Any submission for longitudinal cohorts is assessed as part of wider programme and project grants, with study investigators often needing to make multiple submissions to secure short to medium-term project (nested within these larger longitudinal cohorts) grants to address narrow and specific research questions. Researchers also have to apply to other funding bodies such as Maurice and Phyllis Paykel Trust, Ministry of Business, Innovation, and Employment to obtain the required funding.

Yet, longitudinal cohorts are critical to meeting three of the four strategic priorities outlined in the New Zealand Health Research Strategy 2017-2027<sup>21</sup> – investing in excellent health research that addresses the health needs of all New Zealanders; building and strengthening pathways for translating research findings into policy and practice; and advancing innovative ideas and commercial opportunities.

In this section some key challenges and opportunities to making well-established longitudinal cohorts part of our RSI infrastructure, have been discussed.

### 1. Kaitiakitanga and Governance

Kaitiakitanga, governance, and co-design are critical to successful establishment and maintenance of longitudinal cohorts and ensuring that these deliver to our Te Tiriti responsibilities.<sup>6</sup> Current national and international longitudinal cohorts have experienced leadership structures (often comprising of a world-renowned scientific study Director, advisory committee(s), and core staff) in place. Yet, setting up a new longitudinal cohort often requires duplication of organisational, governance and operational undertakings.

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<sup>18</sup> Maximising the value of UK population cohorts. MRC Strategic Review of the Largest UK Population Cohort Studies. Medical Research Council. 2014.

<sup>19</sup> Longitudinal Population Studies Strategy. Wellcome's Longitudinal Population Studies Working Group. 2017.

<sup>20</sup> Statement of Intent 2017 – 2021. Health Research Council of New Zealand.

<sup>21</sup> <https://www.health.govt.nz/publication/new-zealand-health-research-strategy-2017-2027>

Establishing a central national governance and kaitiaki structure will enable greater cohesion, avoid duplication, academic and political leadership, efficient decision-making procedures, consensus building, coordinated communication, monitoring, and managing risk, and oversight of ethical processes.<sup>22</sup> With stability and long-term focus, this governance structure will improve harmonisation of processes and resources between longitudinal cohorts. It will enable collaborative and comparable access to national and international data, greater capacity for health and social system research, and increased knowledge translation and mobilisation. It will also establish and encourage multidisciplinary networks of excellence, and drive focused capacity building in, for example, research, data science, innovation, public health, and research operations.

A governance strategy developed to underpin a central governance structure could mandate conducting transparent, regular review and evaluation (Appendix II) of existing longitudinal cohorts. This will ensure continued efficiency and relevance and developing mechanisms to mobilise necessary human resource and competencies. This governance oversight would be important in advocating for and facilitating (where possible) equitable and nationally representative participation and retention.

Existing and new longitudinal cohorts would benefit from a long-term, stable international advisory board. The international advisory board would bring critical expertise and insight on shifts in the global landscape and emerging scientific and operational challenges to ensure that New Zealand's longitudinal cohorts remain viable and internationally relevant. This international expert advisory board should also periodically review the strategic requirements and priorities of New Zealand's longitudinal cohorts and provide advice on trends and developments in cohort studies and management. The study Director (or their delegated executive) will continue to make all the decisions regarding the study and be responsible for the study design and its continuity.

## **2. Funding and Support<sup>23</sup>**

Longitudinal cohorts require significant investment of time, effort, intellectual input, workforce, and financial resource (at least \$1.2 million/annum; refer to the case study below). Seen as long-term investments from the outset, there is greater awareness of the need for suitable infrastructure to support high-quality national longitudinal birth cohorts. Yet, sourcing sustainable funding for such undertakings are challenging. It requires multiple grant applications, over relatively short cycles, to competing funding calls with no guarantee of continuity for the study (recruitment, data collection, follow-ups, sample storage) or the core research staff. Funding bodies are hesitant to committing funds over a long timescale and are often reluctant to fund preparatory work such as piloting, validation, and strategic planning. This impacts the long-term deliverables of and goals of these cohort studies with a need to

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<sup>22</sup> Ethics and governance of a longitudinal birth cohort. *Paediatric and Perinatal Epidemiology*. 2008.

<sup>23</sup> The costing and funding of longitudinal birth cohort studies. *Paediatric and Perinatal Epidemiology*. 2009.

focus on immediate, short-term deliverables. The value and utility of cohort is also compromised if critical developmental datapoints are missed and biological sampling is foregone or lost due to inadequate curation.

Major national longitudinal cohorts should be base funded by government funding agencies. Longitudinal cohorts begin to mature into highly generative mode after 10 to 15 years of funding. However, they also provide many useful insights in the form of cross-sectional snapshots of the current generation from the very early stages of the project. Given that the scientific value of longitudinal cohorts increases with time, there is a risk of losing their long-term value if they are subjected to short-term funding cycles (such as for clinical or biomedical studies).

It is critical that sustainable, long-term funding is provided for longitudinal cohorts and that this funding also secures employment for the core research staff for the entire duration the study is funded.

### **Case Study**

*The Dunedin Study, in today's dollars, has cost \$60 million over the last 50 years with \$20 million of this being international investment. This is notwithstanding the significant proportion of early establishment work which was voluntary by members of the Dunedin community.*

*Further, the Dunedin study core unit staff were funded externally from its inception to early 2015, when the Director took up a teaching post to strengthen long-term sustainability.<sup>9</sup>*

While the Health Research Council of New Zealand provides contestable programme funding, international research systems have provided dedicated infrastructure-like support for select longitudinal cohorts. For example, there is the UK Medical Research Council's Population Cohorts grant (over 5 years); UK Wellcome Trust's Longitudinal Population Study grant; National Institutes of Health's (USA) U01 grant; National Health and Medical Research Council's (NHMRC) Clinical Trials and Cohort Studies Grants. Recently, in Singapore, the Agency for Science, Technology and Research, along with other research partners provided long-term funding to National University of Singapore to support its cohorts.

Given the substantial investment required, the funding could be focused on a small, select group of cohorts that have demonstrated strategic value to New Zealand and/or demonstrate the potential to do so (for new cohorts) or continue to do so (for established cohorts). Robust assessment must be introduced for renewal of studies that continue to demonstrate value, and criteria for termination of cohorts that fail to deliver (Appendix II).

### **3. Data Infrastructure**

Longitudinal data is broad and accounts for the complexity of diseases/conditions and increases the likelihood of identifying interactions between multiple causative factors.



Longitudinal data also enables studying multitude outcomes rather than one narrowly defined outcome. These datasets are therefore a resource for the wider scientific community including basic scientists, clinician researchers outside the core study team. The non-study researchers can use these existing longitudinal datasets to conduct research in their own areas of expertise/interest, which in turn enhance the value and utility of the cohorts.

However, we are yet to have an integrated national platform that promotes sharing of data among longitudinal cohorts, and with other datasets such as education records, electronic medical records, etc. There is a considerable opportunity here to create such a resource, enable data linkage, and discover important relationships and trends across various datasets. Analytics and insights derived from such data would be valuable in informing policy, practice, and service delivery. Combining data also improves the power of studies and contribute to unravelling aetiologies of relatively rare diseases. A national integrated dataset would also promote proliferation of innovation to capitalise on its health and economic potential. Highest quality and consistent standards of data safeguards (privacy and security), access, and governance would be critical in development and use of such a dataset.

#### **4. Host Institution and Future Structure<sup>24</sup>**

There is potential for the different longitudinal cohorts to learn from each other, co-develop, and share processes and protocols, instead of expending resources reinventing wheels. All New Zealand longitudinal cohorts are hosted by Universities that are independent of the funding bodies. Being linked to a University has some advantages – for example, shoring up the study’s scientific and ethical integrity; more likely to ensure long-term study’s continuity (particularly in countries with short political cycles); a ready environment to introduce training schemes specific to longitudinal cohorts. However, Universities as a host present with some potential drawbacks such as a lack of willingness by the institution to make long-term commitment. An institution may be supportive initially (benefit from additional scientific activity and credit) but over time, with changing circumstances (eg, unforeseen impact due to COVID-19) or senior management turnover, priorities may change, and a longitudinal cohort may suddenly no longer be supported by the host institution. One potential option to prevent abrupt loss of institutional support and ensure ongoing continuity of these studies, is a Strategic Platform Investment.

From a broader perspective (and beyond the scope of this paper), an established, evergreen longitudinal studies infrastructure would help facilitate a more rapid set up of a national longitudinal study needed to address an emerging new threat to health and wellbeing such as the COVID-19 pandemic. An established sustainable infrastructure would prevent re-inventing

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<sup>24</sup> The overall placing and management structure of a longitudinal birth cohort. Paediatric and Perinatal Epidemiology. 2008.

the operational and logistical wheel of thereby enhancing efficiency in pursuit of national good.

## **Recommendations**

### **Recommendation 1**

Develop a national policy on longitudinal cohort studies, with mandate for provision of supporting infrastructure, capability in key host institutions, and standardised processes to set up a new cohort when needed.

*Consider whether the policy should lay a foundation for establishment of a national governance, kaitiakitanga, and oversight function that will enable facilitation and maintenance of longitudinal cohorts.*

### **Recommendation 2**

Commit long-term, independent base funding for continuity of key strategic longitudinal cohorts as part of New Zealand's RSI infrastructure. These strategic longitudinal cohorts should be renewable over the longer term with appropriate periodic reviews that determine whether the cohorts are meeting their deliverables.

Further funding must be made available for sub-studies nested within these strategic cohorts or, where necessary, new cohorts to address a critical current or emerging issue.

### **Recommendation 3**

Establish a stable, central, overarching governance, kaitiakitanga, and co-design structure to reduce strategic, scientific, and operational duplication, provide academic and political leadership, set up efficient decision-making procedures and consensus building, and to commission new cohorts.

The studies should also have an enduring international advisory board that inputs into New Zealand's strategic priorities and their alignment with international focus-areas, monitors shifts in the global landscape, provides insight on emerging scientific and operational challenges, and independently reviews the performance and ongoing relevance of New Zealand's longitudinal cohorts.

## **Conclusion**

Longitudinal data investments are essential to addressing the needs and priorities of the next generations. Existing and new, nationally representative longitudinal cohorts must be designed to be able to investigate multi-faceted research questions, accounting for a broad

range of variables – genetic and biological, psychosocial, medical care and medications, lifestyle, and environmental influence<sup>25</sup> and capturing comprehensive foundational/baseline (prenatal) data. While the national longitudinal cohorts to date have made invaluable contributions to policy and practice, both here and overseas, we need to invest in a national consortium of longitudinal cohorts that follow sequentially and answer the perennial question – *What will life be like for a New Zealand child born today?*

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<sup>25</sup> An Inventory of European Birth Cohorts. International Journal of Environmental Research and Public Health. 2020.

## Appendices

### Appendix I: International examples

#### The United Kingdom<sup>18,19</sup>

The UK hosts some of the world's earliest and longest running series of national longitudinal cohorts. The first longitudinal cohort follows the lives of 17,000 individuals born in a single week in 1958 (National Child Development Study) in Great Britain. The next study, British Cohort Study, was set up follows the lives of 17,000 individuals born in a single week in 1970 in Great Britain, followed by the Next Steps study which follows the lives of 16,000 people in England born in 1989 to 1990. The Avon Longitudinal Study of Parents and Children (ALSPAC) recruited over 14,000 pregnant women between 1991 and 1992, and have followed these women, their partners, and their children since. The Millennium Cohort Study follows the lives of 19,000 children born across the UK between 2000 to 2002.

Two notable characteristics of these British studies are 1) the inclusion of multidisciplinary investigators in the study team, and 2) their continuity with a new longitudinal cohort set up approximately every decade to address the issues and determinants relevant to each next (almost) generation.

Funding was recently announced to pilot a new longitudinal national longitudinal cohort and will initially run from 2021 to 2023. The purpose of a new study is to understand how children born in the 2020s are affected by circumstances such as the effect of the 2007/8 financial crisis and the impact of the COVID-19 pandemic. There are also the increasingly complex family structures and dynamics, a changing work and education environment, the digital revolution, climate change impact, and changing mental health and health challenges – all of which require new data. Advancing technological developments mean new opportunities for data collection via wearables, smartphones. This new study will test these and other approaches.

A key feature of the newly announced national longitudinal cohort is that its commissioning was guided by an independent public dialogue. Critically important, however, is also the infrastructure and funding in place to support ongoing national longitudinal cohorts. The Wellcome Trust, UK has implemented a new strategy for funding (require funding for over five years) longitudinal population studies including cohorts, biobanks, and panel surveys. Since 2007, the Wellcome Trust alone has invested more than £120 million in longitudinal population studies within the UK and internationally. Core support of £5 million is provided over five years. Dedicated Longitudinal Population Study Grants mean researchers can get support to establish, maintain or enhance new and existing longitudinal cohort studies for the benefit of the wider scientific community.

In addition to the Wellcome Trust, the UK Medical Research Council, Department of Health, Economic and Social Research Council are some of the key long-term funders providing core support to the national longitudinal cohorts and the funding is supported by strategy, policy, and cross-agency governance group.

### **Australia<sup>2,3</sup>**

Australia currently invests in two national longitudinal cohorts - Growing Up in Australia and Footprints in Time (longitudinal cohort of indigenous children). The Growing Up study has been running since 2004 and following the lives of 5,000 children and their families, while the satellite Footprints in Time study has been running since 2008 and following the lives of 800 indigenous children.

The Growing Up study is funded by the Australian Government via the Department of Social Services in the 2000/1 Budget. The initial allocation was \$20.2 million for the first nine years, with continued funding of around \$7.8 million per year for the study. The Footprints in Time study is also funded by the Australian Government via the Department of Social Services. Funding for the initial phases of the project was granted in the 2003-04 Budget, and for its first four annual waves in the 2007-08 Budget and amounts to about \$3 million per year. Ongoing funding for the study is secured until the study ceases to be viable due to sample attrition.

There are other international examples of national longitudinal birth cohorts, such as the French Longitudinal Study of Children, Danish National Birth Cohort. However, regardless of precise study features, there is inherent value in investing in a national system of sequential longitudinal cohorts that follow chronologically. This enables the government to invest in the health and wellbeing of future generations.

## **Appendix II: Evaluation criteria**

Depending on the outcome of interest, the sample size, follow-up frequency, and duration of the longitudinal cohorts vary. The type and depth of data collected also varies. Ideally, longitudinal cohorts should be large and collect as much data and as diverse a range of data as possible. However, at times there may be a need for smaller, nested cohort studies.

The following criteria, focused on strategic value rather than conventional methodological evaluation used for other study types, could be considered to evaluate longitudinal cohort studies.

1. The vision and value of the study
  - a. a clear and broad scientific vision that aims to address current and future health issues
  - b. current and future value and strategic proposition of the study

- c. a diverse track record of excellence including academic, health, industry, public policy, impact
2. Utility
  - a. clear strategy and plan for data sharing and enhancing core data
  - b. demonstrating how data could be accessed by other researchers and decision makers
  - c. establishing national and international partnerships and collaborations while demonstrating the value of these
  - d. demonstrating and maximising value through linking data with other longitudinal cohorts, registries, data sources
  - e. engagement strategy with participants, industry, policy makers, practitioners, other researchers
3. Governance and operations
  - a. effective recruitment
  - b. robust data governance protocols (particularly Māori and Pacific data governance and sovereignty)
  - c. clear demonstration of how data privacy and security will be ensured
  - d. robust, routine quality check for data and sample collection and storage
  - e. broad consent (to re-visit), with strong focus on engaging participants to minimise attrition
  - f. clarity about the funding trajectory of the study (what is the envisaged lifetime of the cohort)

Progress of the studies could be measured by building in key performance indicators such as an indicator for:

- population health impact like policy impact
- evidence-informed guidelines
- team effort and productive partnerships
- multi-disciplinary and industry collaborations
- number of peer-reviewed publications by authors who are not the principal or co-principal investigators
- speed of recruitment
- short- and mid-term retention rate
- data completeness
- long-term: clinical practice changed
- number of postgraduate students trained

### **Appendix III: Additional references**

- Longitudinal Studies Strategic Review. 2017 Report to the Economic and Social Research Council.

- Longitudinal Intergenerational Birth Cohort Designs: A Systematic Review of Australian and New Zealand Studies. Plos One. 2016.
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