

GenV submission to The Early Years Strategy Discussion Paper

Summary

The Early Years offer the greatest opportunities for long and healthy lives. Despite this economic and moral imperative, conventional approaches to policy research, design and evaluation are often stymied by critical data gaps and fail to address the equity gap. We need new strategies to help young children flourish, to prevent illness and to manage the complex, connected problems of the 21st century.

Generation Victoria (GenV) supports the Australian Government's focus on the first five years in the Early Years Strategy Discussion Paper. GenV, a new piece of Australia's data infrastructure led by the Murdoch Children's Research Institute, could help amplify Australia's existing data sources to truly measure early years interventions and outcomes in a way that is not currently possible.

GenV's submission will focus on the data required to test Government interventions and measure impact and outcomes. GenV submission complements the Centre for Community Child Health submission on the Early Years Discussion Paper; GenV endorses the Centre for Community Child Health submission.

What is GenV?

Over the last three years, Generation Victoria (GenV) has been in the field building a new piece of Australian multi-purpose data infrastructure, to speed up research and translation and deliver health, education, and social solutions for children over the long term,

GenV is capturing cell-to-society data on a set of Victorian families who are representative of Australian families¹ and is creating the single largest child and parent consented cohort asset in Australia. GenV has already recruited over 90,000 participants, **including 35,000 babies** with recruitment ongoing.

GenV is recruiting families in every single birthing hospital in Victoria. Since mid-2021, GenV has been inviting all parents of newborns in Victoria to participate in the project with their babies, regardless of their family structure. GenV families include single parent, two parent, foster, same

¹ Australian Institute of Health and Welfare (AIHW), Australia's mothers and babies, Web report, updated 14 December 2022, Data table, National Perinatal Data Collection preliminary update 2021, <https://www.aihw.gov.au/reports/mothers-babies/australias-mothers-babies/data>, (accessed 19 December 2022)

sex and surrogate families. The birth window for the main GenV cohort runs for two years (from late 2021 to late 2023). Our presence in birthing hospitals ends after this period, but the door remains permanently open to all children born in this window and their parents. Thus, **GenV's sample can continue to grow over time**, for example by enrichment with later migrant and refugee groups - who are excluded from all other birth cohorts.

This unique statewide design, coupled with best practice community engagement, has resulted in representative parent and child data that includes priority cohorts:

- It is already Australia's largest rural and regional (as well as urban) cohort.
- It offers valuable insights into the Culturally and Linguistically Diverse (CALD) community, because our recruiters reach every newborn equally and offer GenV in multiple languages, and because GenV is large enough to include meaningful numbers of participants from each of many different cultural and linguistic groups. Over 6,700 GenV participants do not use English as their primary spoken language at home and participants speak 70 languages. Somewhat uniquely GenV is collecting data on self-reported ethnicity.
- GenV and First Nations people are working together to include the first whole-of-state First Nations' consented baby and parent cohort embedded in a general cohort. Currently, 1.25 per cent of mothers in GenV identify as First Nations, which is closely representative of the 1.4 per cent of mothers in Victoria who identify as First Nations. Guided by the GenV's First Nations Advisory Group and a GenV First Nations team member, this inclusive program will become an exemplar of how to conduct truly culturally safe First Nations led engagement, research and collaboration. It will build a social contract with First Nations communities with meaningful findings that lead to improved and responsive policy and practice for First Nations people.
- GenV is the only Australian or international cohort recruited during COVID-19.

This growing, and increasingly representative, cohort will provide valuable insights to support Early Years planning, policy and service operation for place-based approaches, particularly among the rural and regional, CALD and First Nations cohorts. GenV is uniquely positioned to explore intergenerational disadvantage and chronic disease with known intergenerational links.

Opportunities of Australia's existing national data assets

GenV commends the Australian Government using the existing vast national data assets in:

- population level data
- the Australian Early Development Census
- other cohort studies such as the Longitudinal Study of Australian Children (LSAC) and the Longitudinal Study of Indigenous Children (LSIC)
- data linkage eg Multi-Agency Data integration Project (MADIP).

The opportunities they provide are outlined in the following table.

National data asset	Opportunities
Population level data	<ul style="list-style-type: none"> • Informative summary information based on data linkage or surveys on a range of social, health and wellbeing issues.
Australian Early Development Census	<ul style="list-style-type: none"> • Rich data about how children have developed at the time they start primary school.
Other Australian Cohort studies	<ul style="list-style-type: none"> • LSAC/LSIC are smaller consented cohorts and include granular information which provide a more complete picture of health and wellbeing.
Data linkage	<ul style="list-style-type: none"> • Data linkage including MADIP, provide a rich array of social, health economic and geographic data including the Census, GP visits and Centrelink information. • Allows the secondary use of existing data for public benefit at low burden to Australian children.

While they include rich data, **none of these data assets can measure outcomes** at a scale required to target the Australian Government’s Early Years priorities and policies to have the most impact and to test whether they have worked. As a result, proxy indicators are currently used to measure outcomes which is not effective or efficient.

Only GenV, combined with existing national data assets, can inform and assess the Early Years Strategy

GenV’s large size, scale, a consented cohort that reflects Australia’s current diversity **is designed to be used with Australia’s existing national assets**. GenV can speed up solutions to complex problems by using GenV’s powerful interventional early life research cohort, that when combined with Australia’s national data assets, can rapidly generate discovery, prevention, and interventions at scale. **Neither can achieve this alone**. Collecting data once, using many times – will transform and amplify preventive opportunities for Australia’s children.

This means that **only GenV's data asset** can be used to:

- Understand whole of life experiences, not just when people access the health and social support service system for care. This includes understanding:
 - A child's life from the day they were born.
 - Baseline data on a whole population, priority population groups or place (urban or region).
 - Children's strengths and children who are mentally and physically well.
 - Who children live with, if they move locations and/or between dwellings.
 - How children have been impacted by COVID-19, including changes in family circumstances.
- Better understand intergenerational issues eg poverty, education, chronic disease.
- Test evidence-informed interventions on those most disadvantaged, diverse communities and place-based approaches, ie GenV size and scale includes meaningful numbers of participants from many different cultural and linguistic groups, priority cohorts and urban/regional places.
- Test evidence-informed stacked or multiple interventions - which mimic how children experience government policy and strategy in real life - reducing time, financial and family burden. Eg playgroups, early childhood education, prevention of family violence.

The Early Years Discussion Paper noted the evidence for a return on investment in the early years is strong, however the Australian Government currently operates in an evidence void, unable to adequately measure, monitor or evaluate whether benefits for children are being obtained nor the return on the Australian Government's investment. Only GenV can help solve complex problems facing children from all ability levels, walks of life and regions and change the trajectory of Australia's children for the better. Only GenV's scale and a consented cohort that reflects Australia's current diversity, combined with existing national data assets, can **maximise the value, impact and outcomes of the Commonwealth's investment in the Early Years.**

Appendix: GenV's design is different to other Australian birth cohorts

Traditional Birth Cohort Studies

- Mothers or one parent only
- Child as the participant
- One language (English)
- Healthy children or illness specific
- Local or metropolitan area
- Permanent residents
- Short eligibility period
- Short recruitment period
- Recruit by referral or random sampling

GenV's design

- Mothers, fathers, other parents, guardians, kin
- Child and parent participant
- 25 translated languages, interpreting methods for additional languages
- Full spectrum of wellness and illness
- Entire state including rural/regional
- All residents: permanent and temporary
- Two-year birth eligibility period
- Open recruitment period
- Multiple recruitment pathways
- Recruit by referral or random sampling

[Redacted content]