murdoch children's research institute

Pre-Budget Submission 2023-24

Summary

Problem	For the first time, the health and wellbeing of this generation will not improve on the health and wellbeing of their parents. COVID-19 has worsened inequity, making this trend particularly pronounced amongst those living in disadvantage. 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.
	More accurate, timely and longitudinal data are needed to help governments evaluate their policy effort, assess whether their spending translates into effective outcomes, and target future spending more efficiently. This is all particularly important when targeting priority populations and investing in research missions through flagships such as the Medical Research Future Fund (MRFF).
Solution	GenV is already the largest child and parent cohort asset in Australia, recruiting families in every single birthing hospital in Victoria. The fact that GenV recruited parents and babies during COVID makes it internationally unique.
	GenV is designed to **'stop describing and start fixing'**. It is multi-purpose, creating a new piece of data infrastructure to deliver health, education, and social solutions for children and adults over the long term. In doing so, GenV can speed up research, translation and utilisation by many (for example, policy makers, service providers and the health and education sector) to benefit public policy on multiple fronts (ranging from broad health, education and social services policy to specific place-based initiatives targeting disadvantage and poverty).
	This is only possible through large scale, nationally representative consented cohorts.

Investment	A $30 million Commonwealth investment, over three years, will build the infrastructure necessary to establish vital linkages with national datasets and leverage GenV as a national asset, on a national scale.

Doing so will build on $60 million worth of existing investment, along with three years of active fieldwork, for the benefit of Australia's children and families. GenV has already attracted $30 million from the Victorian Government and $30 million from philanthropic sources. |
| **Impact** | This population-based dataset will actively inform and evaluate policy, facilitate agile adjustments in policy thrust and direction, and shape precise interventions. Findings from the unique cohort will benefit priority population groups across the country, particularly those living in disadvantage. GenV will drive lasting evidence-based decision-making and resource allocation.

GenV's **parallel cohort of babies and parents** offers insights into the early and mid-life stages to inform multiple policy agendas, including prevention, early years strategy and chronic disease prevention.

Findings could be applied to flagship Commonwealth policies from as early as 2025. |
| **Policy Alignment** | From as early as 2025, the GenV dataset could help the Commonwealth assess the cumulative impact of its landmark initiatives, such as the Cheaper Child Care policy, changes to Parental Leave Pay and the benefits of increased women's safety funding on children's development, as well as inform future Wellbeing Budgets. It will provide essential data infrastructure to help assess health, education and social solutions, such as the Early Years Strategy, the Care Economy and the establishment of an Australian Centre for Disease Control. |

Working with, and for, the community

Since 1986 the Murdoch Children's Research Institute has grown to become the largest child health research institute in Australia and in the top three child health research institutes worldwide for research quality and impact.

Our research improves the lives of millions of children each year. Our team of dedicated researchers are making discoveries to prevent and treat childhood conditions. Those discoveries create better health outcomes for families around the world.

In 2020, more than 1 million children directly benefited from our research, which informs changes in policy and practice in Australia and around the world.

Our vision is to work with researchers, practitioners and policymakers to solve the complex issues facing our children. We aim to improve prevention, prediction, treatments and interventions for ailments like asthma, autism, allergies, obesity and mental illness in children and the adults they will become.

Operating in a unique model with The Royal Children's Hospital and The University of Melbourne, the Murdoch Children's Research Institute is part of a great circle of healthcare and discovery - helping transform child health from the labs straight into the hearts of the communities.

Introduction

Over the last three years, Generation Victoria (GenV) has been in the field building a new piece of data infrastructure to deliver health, education, and social solutions for children and adults over the long term.

GenV is capturing **cell-to-society data** on a set of Victorian families who are representative of Australian families[1] and is creating the single largest child and parent cohort asset in Australia. GenV has already recruited **78,000 participants, including 30,000 babies**. No other Australian, or international, cohort of GenV's size has been recruited during COVID-19.

GenV is a national asset of international interest and significance.

As GenV develops and grows, so does its potential to influence meaningful policy change and improvements on a national scale.

It is time to bolster this unique national asset by integrating GenV's nationally representative data with Commonwealth datasets, policies and practices.

The Commonwealth's policy intervention and evaluation is too often stymied by critical data gaps, including under-represented population groups, a lack of intergenerational data and a poor knowledge of family wellbeing, prior to their interactions with government services.

Our goal is simple - to develop a better approach to child and parent health, development and wellbeing in Australia. GenV aims for better prevention, prediction, treatments and service delivery. GenV can become a lasting and critical piece of data infrastructure that **builds knowledge about parents and children** at a time when the Commonwealth is embarking on leading initiatives, such as the Early Years Strategy, the Care Economy and an Australian Centre for Disease Control. GenV will be a true whole-of-government investment.

Investing in GenV will bolster its capacity to generate and translate research findings into real-life policy in a timely way.

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[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)

GenV is already influencing and informing Victorian Government policy.

Cytomegalovirus (CMV) is a common virus in the herpes virus family. CMV can be dormant in a person's system for many years, and 'reactivate' from time to time.

While individuals are often unaware they have CMV, the risk increases for pregnant women because CMV infects their baby. Congenital CMV (cCMV) in babies can result in deafness, vision problems and/or neurodevelopmental disability (for example, cerebral palsy, learning and behavioural problems).

We now know that cCMV may be treatable if detected in the first month of life - but there is no routine screening for cCMV at birth.

A fast, cheap and accurate screening test will revolutionise how cCMV is detected and make potential treatment more accessible.

The Screen cCMV team is collaborating with the Walter and Eliza Hall Institute of Medical Research (WEHI) to test and validate a new, cheaper technology that works with saliva samples and may become available as a point-of-care test.

GenV will use a small portion of the saliva collected from babies to test for cCMV at scale and find out how common cCMV really is in Australia's newborn babies. It will combine this information with GenV's long term outcomes and services data for health economic analyses. If beneficial and cost effective, the new screen could be recommended to be rolled out for all newborns as part of standard care.

An early, fast, cheap test for cCMV, the most common infectious cause of neurodisability, will allow urgent treatment that changes the lives of many children.

The Screen cCMV project is funded by a 5-year NHMRC Clinical Trial and Cohort Studies Grant (2006491) and is one of a number of projects funded by prestigious research grants, including with the MRFF.

If we are to address inequity for this generation, then we need to ensure that data and research influences policy and practice in a timely way.

Collaboration between the Murdoch Children's Research Institute, The Royal Children's Hospital and The University of Melbourne has resulted in a dynamic approach that overcomes the traditionally slow pace of research and discovery.

This is an optimistic, inclusive, positive and progressive proposal to drive societal benefit at a low burden to the community. GenV will function as an antidote to the anxiety, uncertainty and isolation of recent years.

This submission is seeking a $30 million Commonwealth investment, spanning three years, to leverage GenV as a national asset and integrate it with Commonwealth datasets.

GenV will inform evidence-based decision making, particularly amongst priority population groups.

Meaningful findings could be available from as early as 2025.

A national data asset to inform the policies that transform lives

For the first time, the health and wellbeing of this generation will not improve on the health and wellbeing of their parents. COVID-19 has worsened inequity, making this trend particularly pronounced amongst those living in disadvantage.

Accepting the status quo leads to poor adult health, reduces national productivity and costs governments billions of dollars. This is compounded by the fact that COVID-19 has worsened inequity.

The Productivity Commission's 2017 *Shifting the Dial: 5 year productivity review* points to the urgent need to reduce low-value health interventions and use information better.

Conventional approaches to research fail to progress at a responsive pace and it is estimated that, currently, 85% of research dollars are wasted[2]. Our ability to address these complex issues is failing to keep up with demand.

A new approach is needed to ensure that today's children and parents are not faced with an increasing burden from complex health and development problems, such as mental illness, obesity, learning difficulties and allergies.

GenV is capturing cell-to-society data on families to inform the way we manage four key challenges:

- Reduce the inequitable burden of modern epidemics for children, such as school failure, depression, obesity, asthma, allergy and antisocial behaviours,

- Turn around the unprecedented rates of adult diseases (such as heart disease, diabetes, mental health, kidney failure, osteoporosis),

- Change how large scale research happens, (currently, traditional research methods are too cumbersome, short term and costly to scale up to the level needed), and

- Reap the full benefit of investment into our excellent health and educational services (recognising that our statewide data infrastructure is currently under-utilised for innovative solutions).

GenV is designed to **'stop describing and start fixing'**. It has the capacity to transform - on a national scale - how we test policy, practice and medical interventions and design better prevention, early intervention and tailored care for children and their parents. This is only possible through large scale, population-representative consented cohorts.

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[2] Macleod MR, Michie S, Roberts I, Dirnagl U, Chalmers I, et al. (2014) Biomedical research: increasing value, reducing waste. Lancet 383:101–104.
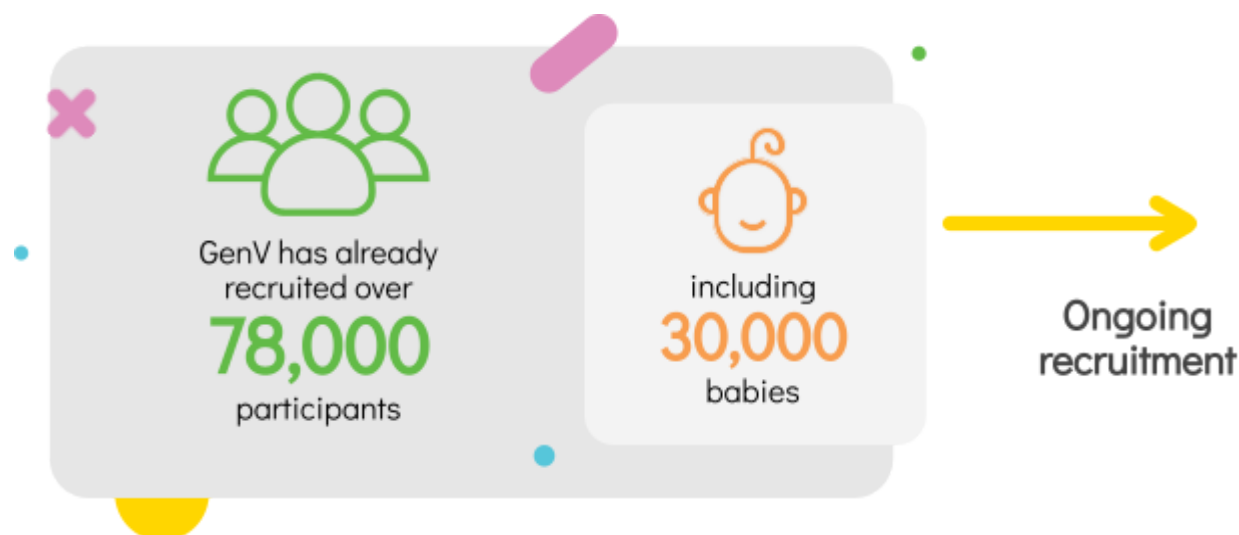
Our experience - GenV

GenV is the largest child and parent cohort asset in Australia, recruiting both babies and parents to **capture key data at the early and mid-life stages**. Its scale will help solve complex problems facing children and parents from all ability levels, walks of life and regions.

GenV is multi-purpose - it is a new piece of data infrastructure to deliver health, education, and social solutions for children and adults over the long term, while also speeding up research translation and utilisation. We envisage GenV being used by a range of influential policy makers and practitioners across a broad range of policy areas, including health, education and social services policy, to specific place-based initiatives targeting disadvantage and poverty. For example, the data will help Primary Health Networks (PHNs) inform their community health needs assessments and place-based commissioning decisions, as well as evaluate their impact.

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 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.

GenV has already recruited over
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Ongoing recruitment

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 5,000 GenV participants do not use English as their primary spoken language at home and participants speak 65 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 GenVs 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 planning, programming 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.

Data collected from this cohort will help answer critical questions about the short, medium and long term effects of COVID-19, which will result in important research findings of global significance.

The GenV program has established significant pieces of core infrastructure. This includes the prototype LifeCourse Repository to hold large scale data in multiple formats (biologic, survey, images, video, administrative) and the southern hemisphere's largest -80°C robotic biobank, in addition to the necessary planning, ethical and governance approvals. In the process, we have established wide-ranging clinical, research and policy partnerships.

GenV's design comprises a series of building blocks:

Consented birth and parent cohort	Biosamples	Linked administrative and clinical/service data	GenV and Me	Solutions Hub

Platform as a service

The research data **culminates in an e-platform**, which is the epicentre of the project. The e-platform seeks to capture digital data, providing a product for research that will improve the health and well being of future children and adults. This may happen via the health, social and educational sectors, diagnostic and pathology companies, and the global research community. Maximising participant recruitment and follow up (including with priority cohorts), the very large GenV cohort will provide opportunities to develop digital health and artificial intelligence applications, and minimise the cost and burden of interventional research including randomised trials.

The platform will comprise physical, IT, digital and data assets, including data analysis, data visualisation tools, data quality management including products such as data dictionaries, integrated studies management, legal, governance and ethical design and management, and participant recruitment and cohort management.

New Commonwealth funding for GenV will take this platform from a prototype to a fully fledged national asset that integrates with Commonwealth data and is available to a range of users.

The Solutions Hub will be the 'engine room' for active translation and utilisation of the data. The Solutions Hub is where collaboration, science and capacity building will drive and translate findings and knowledge into actions and interventions. The Solutions Hub will help policymakers determine policy gaps and solutions, including the ability to 'course correct' through evidence-based interventions. The Hub will lead cross-sector collaboration, knowledge sharing and translation on a scale that is unique within the research community.

A Deloitte business case in 2018 identified that GenV will enable early interventions and targeted prevention strategies, which lead to a greater understanding of child and adult health and the opportunity to develop and test more precise interventions, as well as a faster evaluation. GenV is a long term project, designed to run across decades with the potential to fill in gaps in understanding of children's health, development and wellbeing, as well as healthy aging for their parents.

GenV and Me is the purpose-built App that helps us stay in touch with families, and allows parents to add data over time. As GenV children grow, so does GenV. GenV and Me sends out a new 5-minute survey at multiple points throughout the year.

Each survey has questions and other activities (like recordings, photos and game-like assessments). Parents tell GenV how they and their child are doing on important issues – like quality of life, health conditions, development, sleep, feeding, and being a parent. Its content is guided by parents, professionals and research experts. Launched in May 2022, we continue to improve the tool through rapid development. For now, it's in English only. Soon, it will be in many languages.
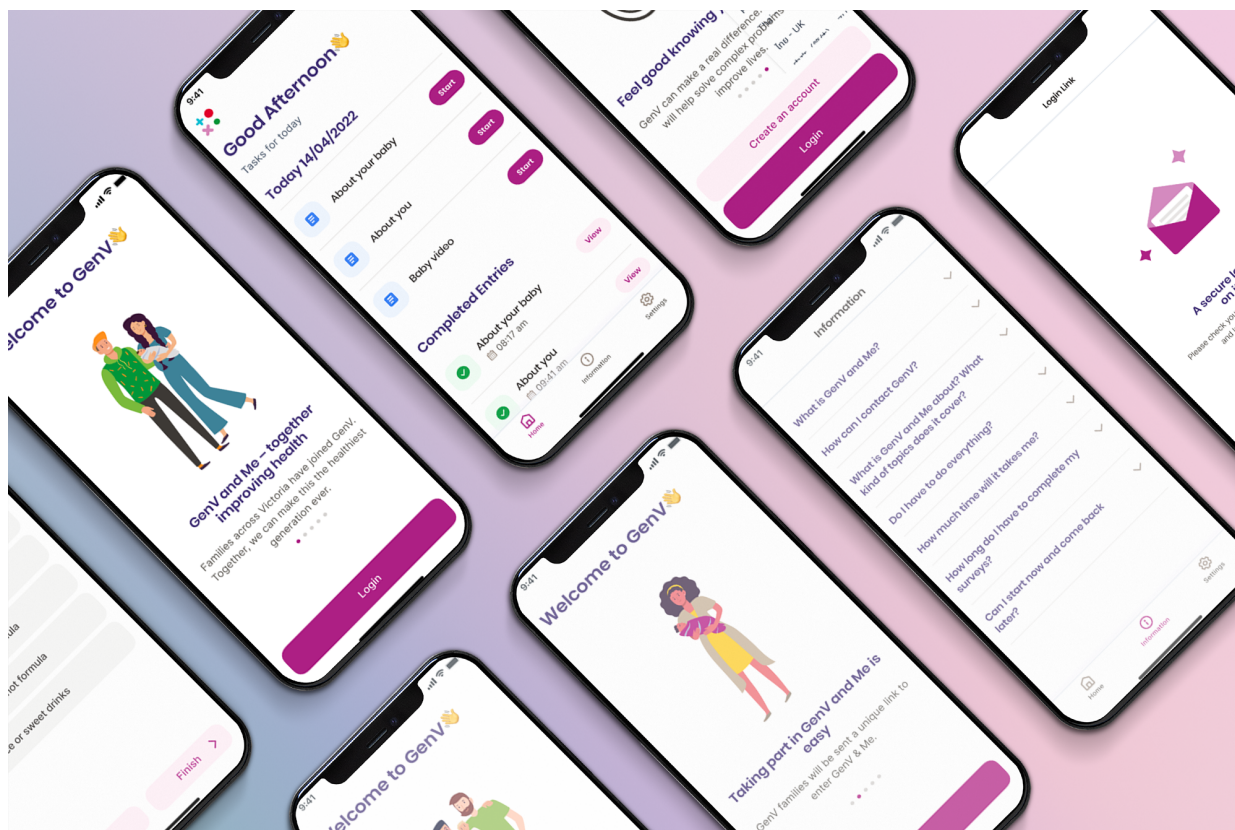
Immediate policy imperatives for a national expansion

Commonwealth investment is required in order to leverage this data asset to deliver health, education and social solutions on a national scale, in a timely manner.

GenV offers the Commonwealth a cell-to-society dataset from which to measure the impact of a series of flagship policies, and to inform further policy refinement and improvement over time. No other data asset has the necessary depth and breadth to effectively evaluate Commonwealth policy initiatives at scale.

The Commonwealth has an opportunity to build on $60 million of existing investment, along with three years of active fieldwork, for the benefit of Australia's children and families. GenV has attracted $30 million from the Victorian Government and $30 million from philanthropic sources.

This vital dataset would help address the high burden and inequities of modern childhood problems by providing a complete picture of the health and wellbeing of an entire generation, including intergenerational disadvantage, and by testing solutions to address them.

We know that it is not one single factor that starts a child on the path to adult disease and disorder, but the interaction between their genes and the environment and context in which they live and grow. Changing children's environment and context for the better offers a chance to improve the health and wellbeing of all children - not just in childhood, but across their entire lifespan. Many diseases and disorders in adult life, including major public health concerns such as obesity, heart disease, and mental health problems, are linked to processes and experiences that happen in very early childhood.

GenV data would be available from as early as 2025 to help the Commonwealth assess the cumulative impact of its policies impacting both the early years (children) and mid-life adults (their parents, who have much to gain from effective prevention). This includes the Government's landmark policies in prevention (Australian Centre for Disease Control), the early years (Cheaper Child Care Policy and Early Years Strategy) and disadvantage (Closing the Gap in early childhood). GenV will also provide instructive findings to help inform future Wellbeing Budgets, as well as measure how the overall investment in Ending Violence against Women and Children improves the health and wellbeing of children and parents.

As a consented parent and child cohort that is representative of lower socio-economic groups, GenV is uniquely placed to explore intergenerational disadvantage and chronic disease with known intergenerational links. GenV data could also help Australia track and manage its targets around the UN's 17 Global Sustainable Development Goals.

Given the careful approach to recruitment of priority populations, GenV offers the Commonwealth an opportunity to engage CALD and Aboriginal and Torres Strait Islander communities in public health research as they recover from COVID-19. This will have particular utility in identifying, designing and implementing place-based programs and solutions.

GenV provides an opportunity to better understand the implications presented by COVID and natural disasters. GenV recruited families during COVID-19 pandemic and recent floods, and will follow them through many other events. GenV has the capacity to mount rapid data collection waves at these times to probe their impacts in real time for those affected compared to those who were not.

GenV will allow the Commonwealth to unlock additional insights into the impacts of climate change, natural disasters and pandemics on the physical and mental wellbeing of children and families.

The data set combines valuable exposure data (eg exposure to a policy) with outcome data (eg child and parent health and wellbeing). This will allow the Commonwealth to unlock additional insights into the impacts of climate change, natural disasters and pandemics on the physical and mental wellbeing of children and families. Doing so will help address these impacts and inform future disaster/pandemic planning, in a way that is not possible based on existing data.

Existing cohort data across Australia is often siloed and under-utilised due to a lack of integration and interoperability between State and Commonwealth datasets[3]. Furthermore, the current pace of traditional research means the timeline to effective scaling and impact is not aligned with community, policy and political aspiration. Because researchers essentially have to build their datasets from scratch for each new question, Australia is unable to address inequity for this generation. GenV is designed to address these barriers, creating a flexible and timely resource that researchers and policy makers can tap into as questions arise.

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[3] Australian Institute of Health and Welfare (AIHW), Australia's Health 2022: Data Insights, https://www.aihw.gov.au/getmedia/c91a05ef-307f-4c18-8ed3-dfe33d0c603d/aihw-aus-240.pdf.aspx?inline=true (accessed 24 November 2022)

International precedents for effectively using a geographical database on a national scale

In **New Zealand**, the Dunedin Multidisciplinary Health and Development Study has followed 1,037 babies born at Queen Mary Maternity Hospital between 1 April 1972 and 31 March 1973. The study is now in its fifth decade and has resulted in more than 1,300 publications and reports, which have informed policy makers across New Zealand and overseas.

In the **United Kingdom**, the Born in Bradford (BiB) study has tracked the lives of over 40,000 people in the city of Bradford. This is informing new and practical ways to work with families and health professionals. For example, BiB helped establish screening for gestational diabetes for all pregnant women in their catchment, increasing detection rates from 2 per cent to 7 per cent. Members of the BiB research team are now working with the National Institute for Health and Clinical Excellence to establish national guidelines around diabetes in pregnancy.

Researchers in **Canada** have captured an unprecedented pool of early life human genetic, epigenetic and microbiome data as part of the CHILD Cohort Study. The study recruited around 3,500 pregnant women in four provinces (Vancouver, Edmonton, Winnipeg and Toronto) and is following their children from before birth to school age and beyond. Findings from these province-specific studies will help inform personalised medical practice, parenting choices, consumer product regulations and policy development for healthy communities across Canada.

Taking a similar approach, GenV will drive more equitable lifetime health and wellbeing, more efficient use of funding and better long term economic outcomes, through the increased productivity that results from improved health, education and wellbeing.

Funding recommendations

GenV is seeking a $30 million investment to bolster this unique national asset through integration with Commonwealth datasets, policies and practices.

Commonwealth investment will shape and scale the national opportunity to leverage and translate the data from this Victorian cohort into policy insights and assessments for that benefit families, in all their diversity, across Australia.

This funding request will match the $30 million provided by the Victorian Government and can be considered in three complementary parts.

01.

The first and immediate imperative is to ensure that the cohort remains large, diverse and representative across population groups.

Commonwealth funding will ensure ongoing and expanded engagement and enrollment with priority population groups, including First Nations, culturally and linguistically diverse and rural and regional families.

Based on learnings from the GenV program so far, we know that best practice engagement processes for these cohorts are costly. They require interpreters and staff with specific skills, and add complexity, time and cost to data and IT systems.

02.

To leverage this uniquely representative cohort within two years, we will take the existing data repository to scale and integrate with Commonwealth datasets.

Commonwealth funding would ensure that all the e-platform processes are established for full end-to-end service offerings to enable users, including policymakers, service agencies (such as PHNs) and communities, to begin accessing this valuable data by as early as 2025.

03.

The National Solutions Hub will drive solutions to today's complex problems for young children and adults.

GenV's data integration will be co-designed with the Commonwealth to maximise advantage for policy design and assessment, delivering key insights by 2025.

This work will provide the social and environmental data the Commonwealth needs to measure the quality of life indicators that are more difficult to capture than the macroeconomic factors traditionally contained in a Federal Budget.

By 2025, GenV will also be established as an Intervention Hub that can test individual (via clinical trials) and population (via policy trials) interventions.

In doing so, GenV will provide data and knowledge for the Commonwealth to achieve its ambition to Measure What Matters and deliver its Wellbeing Budgets.

> A $30 million investment, over three years, to leverage this unique dataset on a national scale, will place Australia at the forefront of health and social research that solves nationwide problems in a timely, inclusive and lasting way.

Conclusion

GenV will revolutionise how we solve complex issues affecting children and their parents to ensure we have the healthiest generation to come.

It aims to deliver the relevant and timely insights needed to solve the major health and social problems facing children, and accelerate prediction, prevention and treatment for all Australian children and their parents.

It will transform how we test policy, practice and medical interventions and design better prevention, early intervention and tailored care for children and their parents, which is only possible through large, population representative consented cohorts.

With Commonwealth support, GenV's **cell-to-society data** will be available to all Australian researchers and policy makers to help measure the impact of flagship policies, and to inform further policy refinement and improvement over time. GenV will provide powerful parallel insights into both the early years and mid-life.

There is no other platform that can effectively evaluate the wide and growing range of current and future Commonwealth policy initiatives.