

GenV executive summary

Accelerating healthier solutions for today's children & tomorrow's adults

The health of our children is more important now than at any other time in our history. Their emotional resilience and good health are vital both individually and collectively, especially in the context of ageing populations¹. Generation Victoria (GenV) aims to conduct and support fast, responsive and flexible research on a large scale, so that our children reach their full potential supported by happy, healthy, highly-functioning and productive adults.

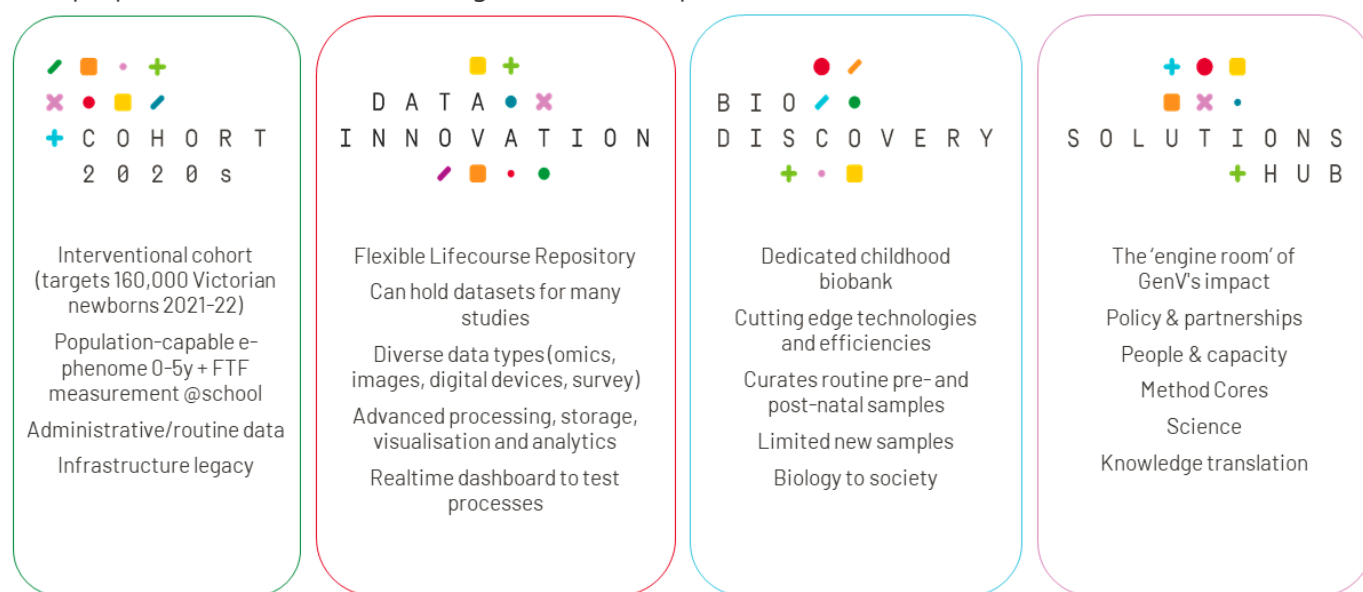
Without action we risk going in the opposite direction. The health of this generation of children is shaping up to be worse than that of their parents. Despite steady improvements in some areas (e.g. smoking, road traffic accidents and mid-life heart disease), Australia is facing a late-life tsunami of chronic conditions like diabetes, kidney failure, deafness and Alzheimer's – many traceable back to childhood. Children themselves face their own immediate problems like obesity, low literacy, autism spectrum disorder, preterm birth and poor mental health.

Unfortunately, research and evaluation methods have proved slow to address these issues. Current approaches essentially reinvent the wheel for every new research project in a way that is poorly coordinated, cumbersome, and wasteful. We need faster routes to better disease and risk prediction, prevention, treatment and service equity.

GenV proposes to build a single multipurpose research platform that can rapidly and safely deduce problems, test interventions and evaluate solutions to deliver benefits for children on many fronts. It is designed to:

- Be inclusive, in order to benefit the most vulnerable individuals and communities;
- Span the full spectrum of population health from wellness to disease;
- Move from a sample to a population basis, supporting diverse interventional research;
- Be affordable and sustainable; and
- Attract the talent and investment needed to use the resource for its fullest benefit.

GenV proposes to commence recruiting in 2021. It comprises four main arms:



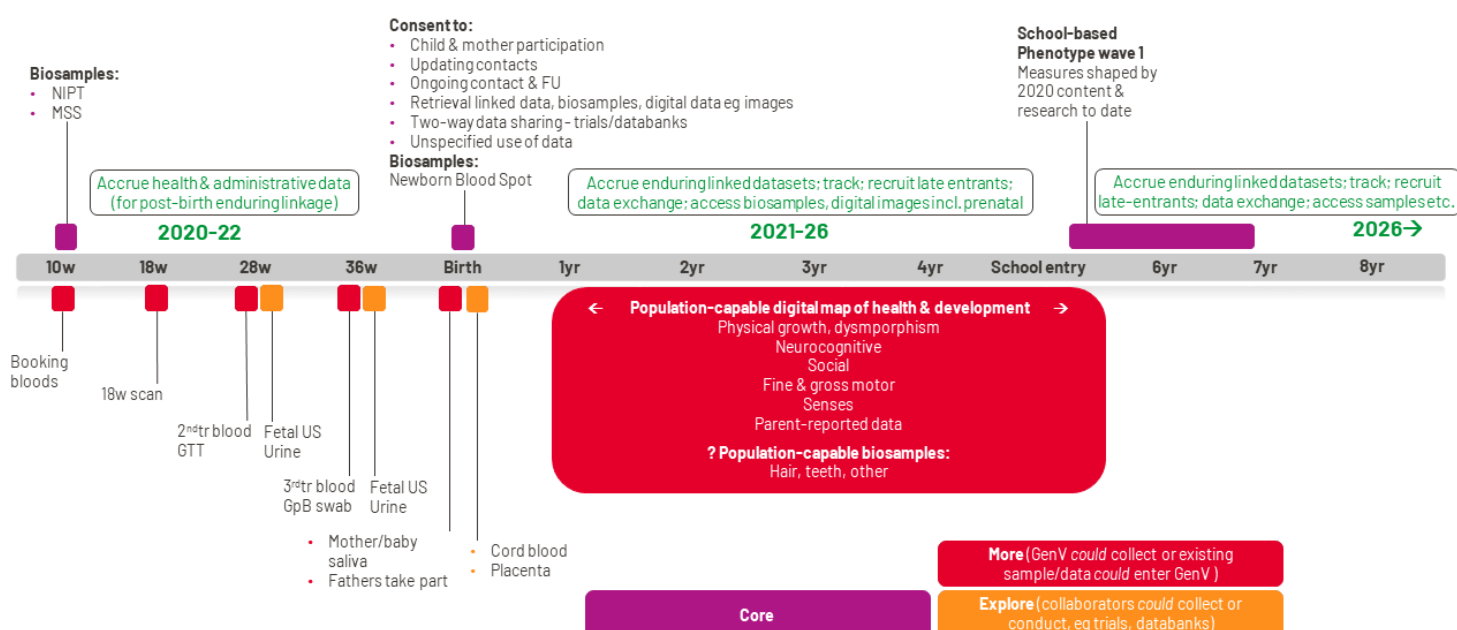
https://www.childrenshospitals.org/-/media/Files/CHA/Main/Research_and_Data/Pediatric_Health_Care_Trends/2017/the_new_importance_of_children_in_america_report_101217.pdf

GenV's design

The proposed design of the GenV cohort is shown below. The "Core" elements (above the line) comprise:

1. Consent soon after birth, targeting all 170,000 babies born in 2021-22 and their parents;
2. Curation of two existing universal biosamples (NIPT, NBS) that come to the Melbourne Children's Campus;
3. Ongoing access to extensive administrative datasets, including those collected prospectively prenatally; and
4. Face to face direct assessment once at school.

Below the line are examples of potentially exciting additional elements currently being scoped. 'More' refers to data and samples that (a) are already collected on a statewide level and could potentially move into centralised research quality curation, or (b) could be universally collected by GenV itself. 'Explore' refers to new data and samples that could potentially be collected by collaborators or services with the right support and endorsement.



GenV's progress and timelines towards recruitment in 2021-22

- In December 2017, the Victorian Minister for Health launched the GenV program. \$40 million of philanthropic and state government support are confirmed for the GenV Foundation phase over the next 4 years. GenV is now seeking substantive co-funding.
- In 2018, we:
 - built the prototype GenV LifeCourse Repository
 - generated funds to grow LifeCourse capacity ahead of GenV
 - commenced the design and documentation phase
 - set up high-throughput processes to support GenV's many working groups and other inputs/outputs
 - began to work with other new state-based birth cohorts around Australia with a vision of coordination to achieve the best mix of uniqueness, complementarity and harmonisation.
- 2019 sees detailed design, ethics submissions, piloting, commissioning and state-wide engagement.
- In 2020, we will operationalise and test GenV, the first mothers will become pregnant (and potentially enter Depth cohorts), and we will recruit our Vanguard cohorts.