

# GenV: Adding value to Maternal and Child Health to inform future practice and drive better health and wellbeing outcomes

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27 May 2022

*The Murdoch Children's Research Institute acknowledges the Traditional Custodians of the land upon which we are located. We pay our respect to their Elders past, present and emerging.*



The vision and possibility of GenV

# GenV is about the future of the next generation

GenV is designed to address problems:

- Slow pace of discovery and translation in research
- Poor returns on the information that services already collect
- High burden and inequities of modern childhood problems
- The growing threat of adult chronic diseases



# The problems pregnant mothers face



## Maternal problems:

- + Preeclampsia-Spectrum Hypertensive Disorders of Pregnancy
- + Postpartum haemorrhage
- + Gestational diabetes
- + Perinatal depression
- + Placental abruption, late spontaneous abortion and preterm premature rupture of membranes etc

## Neonatal problems:

- × Fetal Growth Restriction
- × Stillbirth
- × Preterm birth
- × Large/small for gestational age
- × Admitted to SCN/NICU
- × Brain injury/CP
- × Chronic lung disease etc

# The problems children face



## From infancy to age 14-15 years:

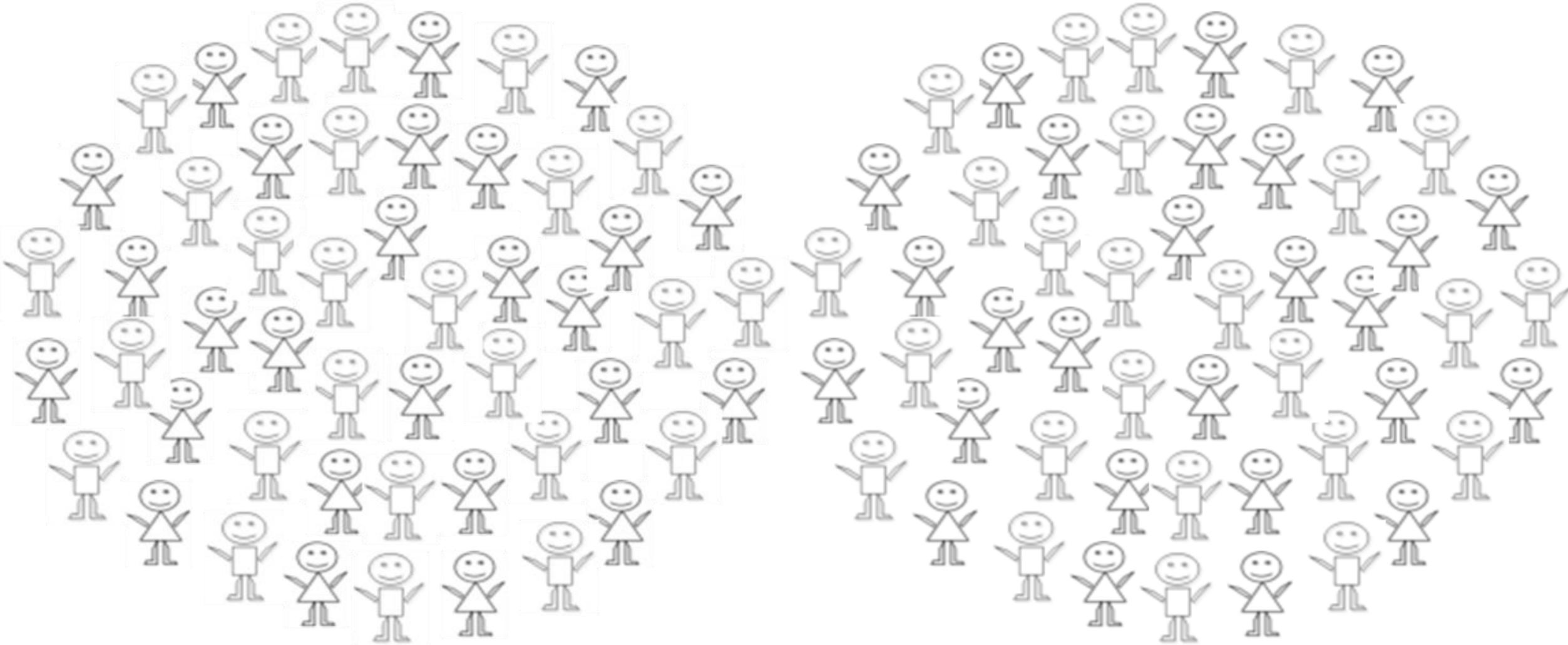
- $\geq 60\%$  of children  $\geq 2y$
- $\geq 70\%$  of children  $\geq 8y$

have at least one ongoing health or psychosocial problem at any given time.

## This translates to:

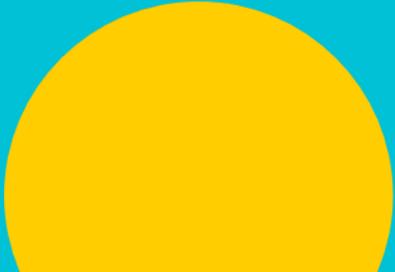
- ✔  $> 500,000$  with mental health problems
- ✔  $> 700,000$  with allergies, eczema, asthma
- ✔  $> 200,000$  obese or seriously obese
- ✔  $> 57,000$  start school vulnerable in one or more areas of development
- ✔  $> 350,000$  child abuse notifications last year
- ✔ Plus increases in autism, ADHD, school problems, violence and aggression...

How can we keep children, as individuals and as populations, healthy and developing well?





By 2035, GenV's vision  
is to have helped solve  
complex issues facing  
our children and adults  
now and tomorrow



Very large studies are transforming how  
policy and practice questions are addressed  
for older adults.

GenV wants to do the same for  
children and parents.

It is funded by the Paul Ramsay Foundation  
and the Victorian Government.



By 2035, GenV's vision is to have helped solve complex issues facing our children and adults now and tomorrow

**Primary Objective:** To create large, parallel whole-of-state birth and parent cohorts.

Can support a very wide range of research, service and policy into common and uncommon conditions facing children and adults today and to span wellness through illness.

Designed to support better prediction, prevention, treatment and service delivery.

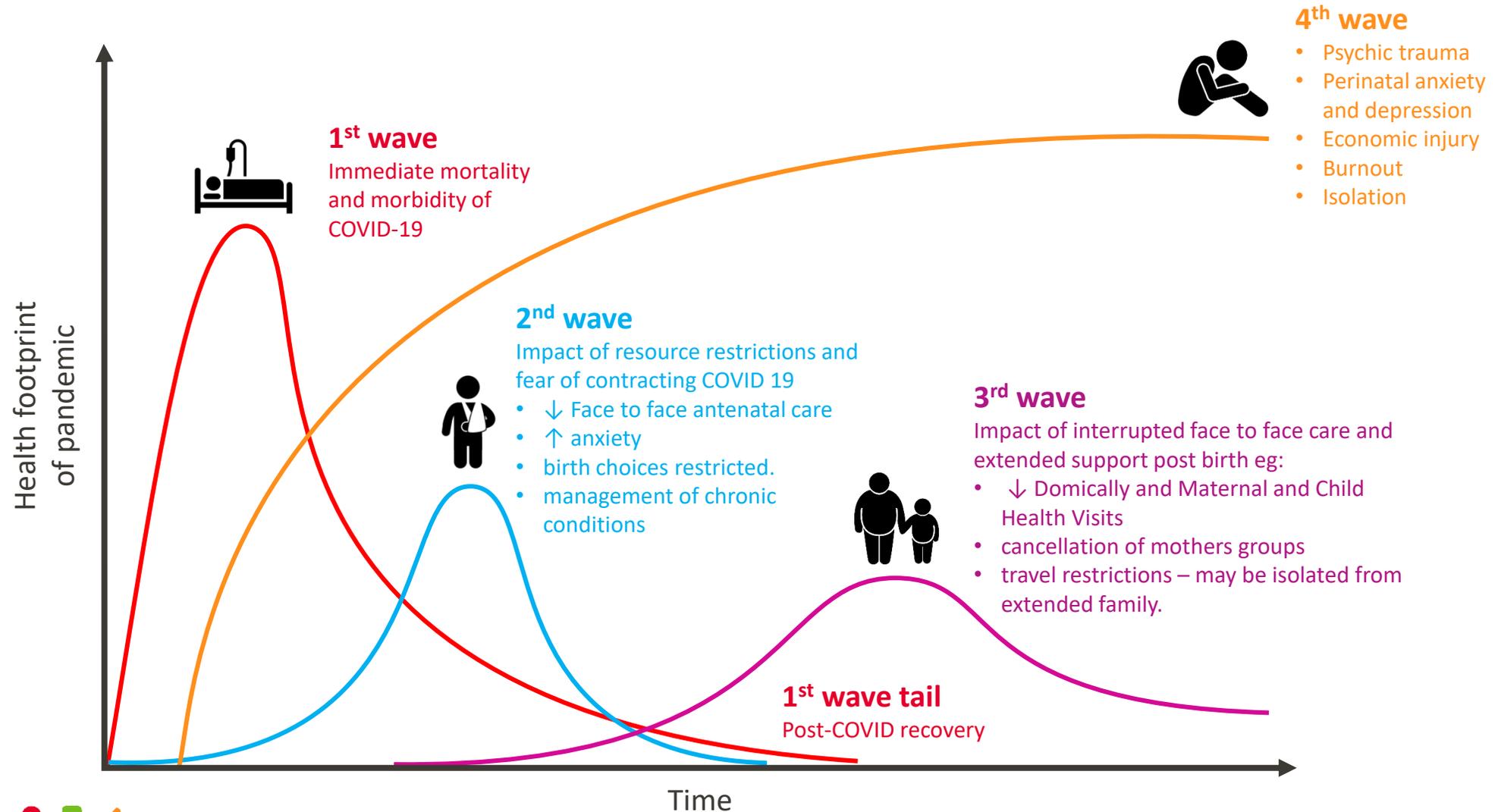
# GenV focus areas





# COVID-19's 4 waves of impact - on birthing women and families

GenV is positioned and ready to help understand and mitigate all 4 waves of impact



# GenV could answer critical research questions, for example:

## 1st Wave (Immediate mortality and morbidity of COVID-19)

- What were the true rates of COVID in pregnancy? Where & when?
- What were its impacts by trimester, including vertical transmission?

## 2nd Wave (Impact of resource restrictions on urgent non-COVID conditions)

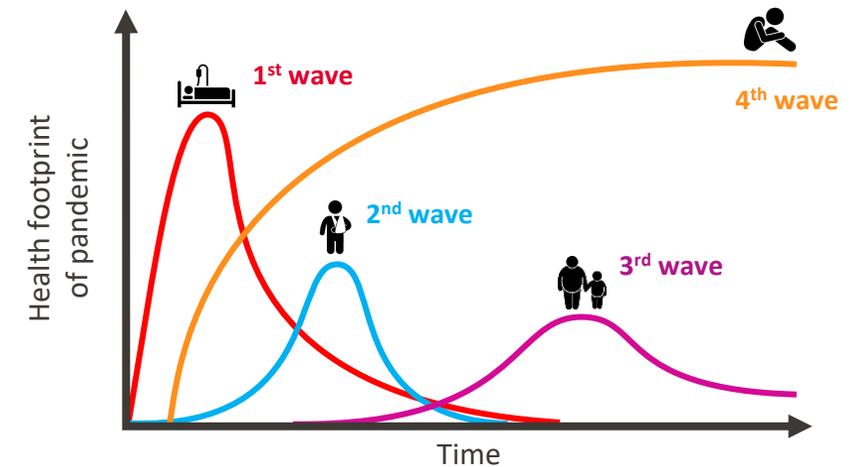
- What are the impacts of unprecedented antenatal & MCH changes on:
  - Screening rates & mother/child impacts on health/development?
  - Labour and postnatal experience and physical/mental health?

## 3rd Wave (Impact of interrupted care on chronic conditions)

- What are the long term impacts of COVID-driven service changes on other conditions?
- What are the benefits vs costs and harms of high telehealth rates?

## 4th Wave (Long-term impact, eg. Psych trauma, Mental illness, Economic injury, Burnout)

- What strategies work best to get individuals and communities back on their feet?
- Why do some communities recover faster than others? What was the pandemic's impact on rural communities?
- How did the pandemic impact on inequity? mental health (including fathers/men)? important population subgroups?



# What is the GenV solution?

1. Invite 150,000 newborn babies and their families across Victoria into the world's largest research cohort



2. Collect routine health and wellbeing data, including saliva and biological samples, from babies and parents



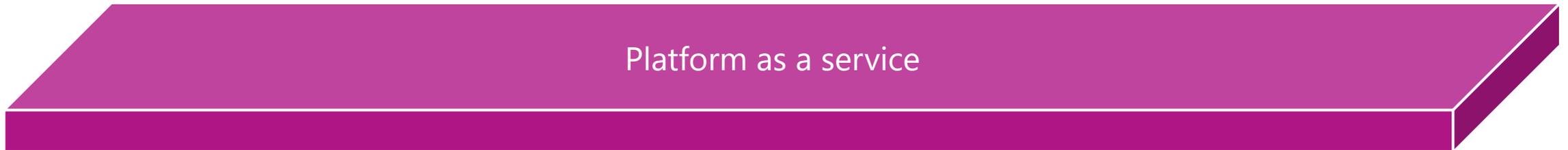
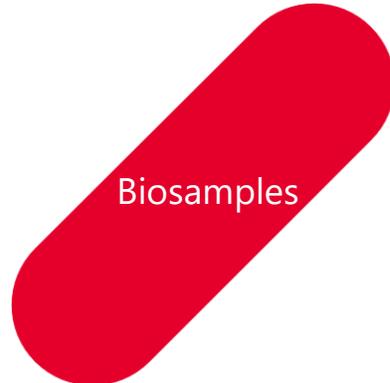
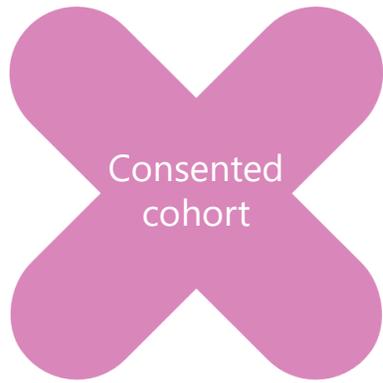
3. Enable researchers to use the data to identify patterns and discover how we can predict, prevent and treat health and wellbeing problems faster and more accurately than we can today



4. The findings are used to shape the way health, education and social services are delivered, improving the health and wellbeing of children and their families across Victoria – and beyond



# What is GenV?



# The GenV guiding principles

1

## Collaboration

GenV should **increase partnerships** and links between researchers, clinicians, policy makers, service providers and the community

2

## Inclusivity

GenV should be **inclusive** of all partners, participants and data users

3

## Sustainability

GenV should be **financially sustainable, leverage infrastructure and capabilities**, and be **scalable** to respond to emerging insights and needs

4

## Enhancement

GenV should be **low burden to its participants** and **enhance services**.

5

## Systematised processes

GenV should operate via **standardised, high throughput processes** that can be embedded to become 'normal practice' in real time.

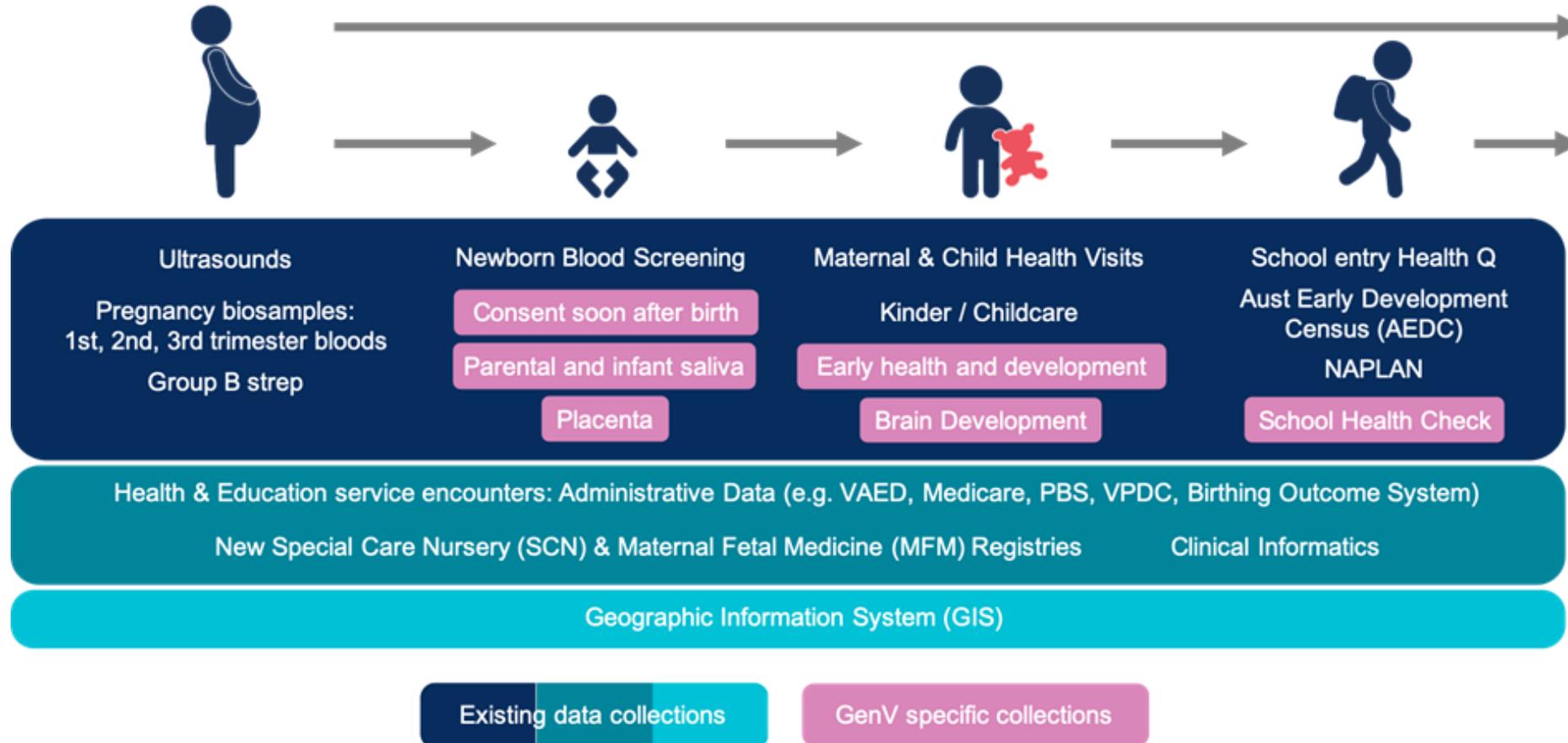
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## Value

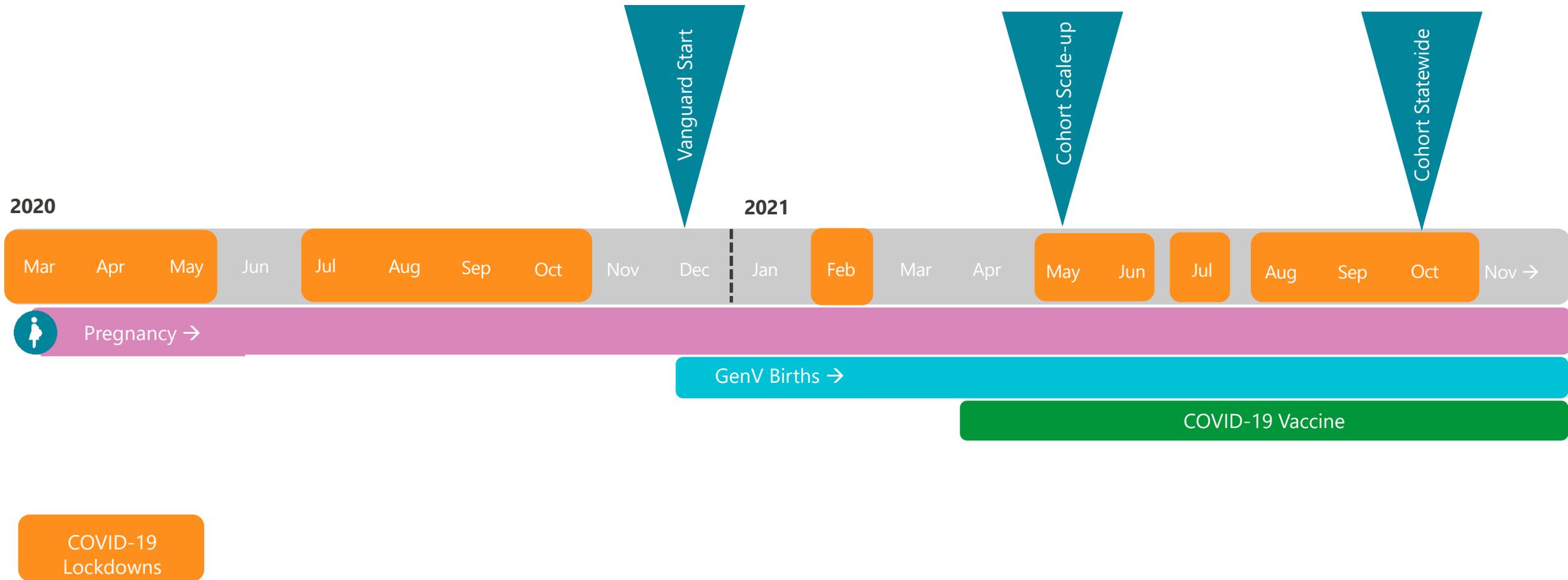
GenV should generate **outstanding science and solutions** that maximise children's and parents' outcomes.

# What is GenV – the participant journey

A whole-of-Victoria cohort targeting all 150,000 babies born from mid-2021 for two years and their parents



# GenV timeline in relation to COVID-19 pandemic



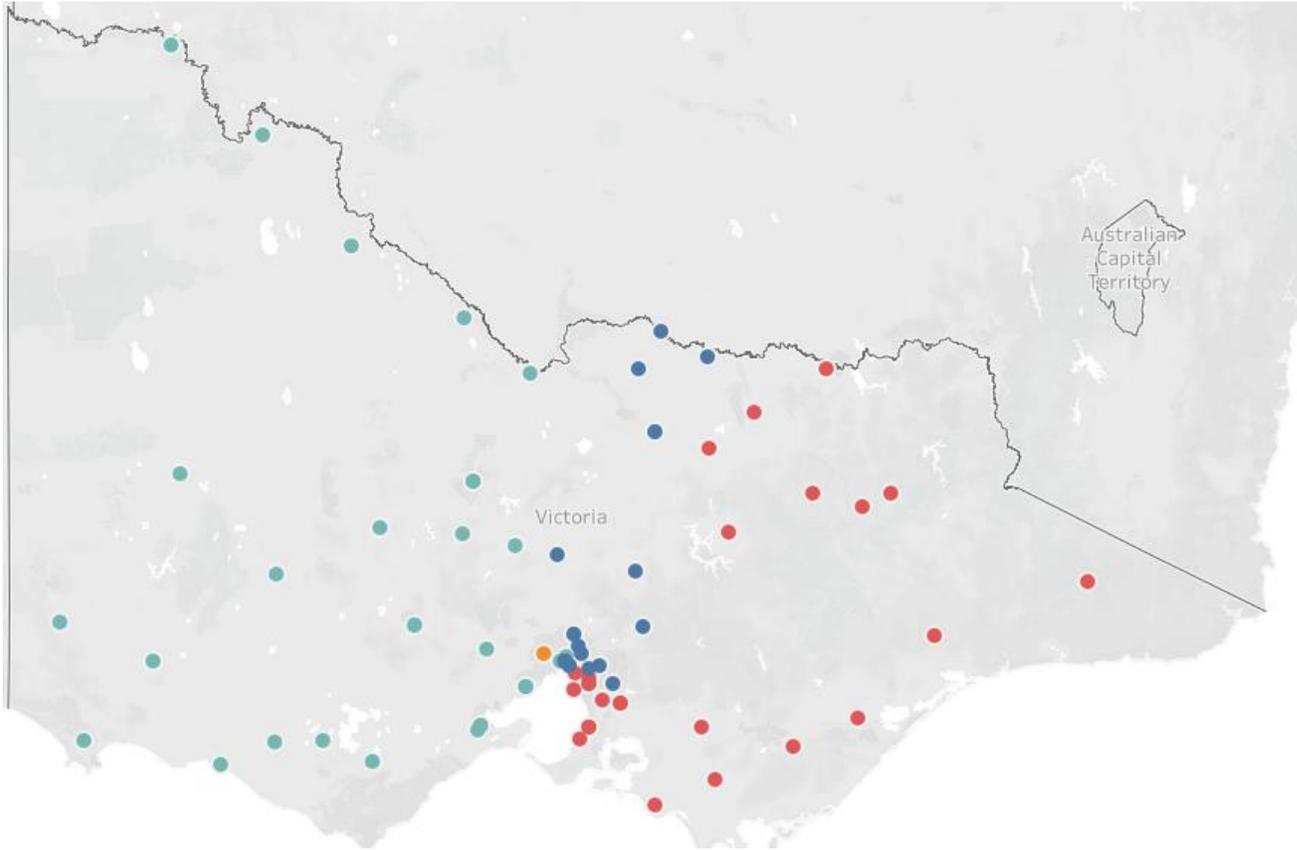
# Recruiting Victorian families into GenV



# Recruitment of families

- GenV information provided to families antenatally
- All conducted by MCRI staff (honorary at Hospital)
- Models:
  - Maternity hospital inpatients
  - VIHSP outpatients
  - Virtual (telehealth) and self-guided if missed
- Opt-in consent
  - eConsent
  - Optional Saliva sample taken
  - Short survey completed
- No impacts on clinical care





**Signed up to GenV**

16,604 babies  
**42,579** participants overall



**58 of 58** (23 Metropolitan, 35 Regional) hospitals



**132** GenV Field team members



**Regional Victoria**

3,560 babies  
**8,857** participants overall



**3,775** participants whose primary spoken language at home is not English



**65 languages** captured by our recruiters (including Auslan)



**35,404** saliva samples  
**55,357** VCGS Samples – MSS & NIPT



Representing all Victorian communities

# GenV's First Nations engagement

Build trust and social contract through community engagement led by Aboriginal people



# Culturally and linguistically diverse (CALD) engagement

Build trust and social contract through community engagement

Training

Translated  
materials

Plain English

Bi-lingual  
recruiters

Place based  
approaches

# GenV value - size and scale to address the big issues

## COVID

"Only very large cohorts can clarify COVID's sweeping consequences"

## Healthy pregnancy

"More precise prediction could prevent the big adverse pregnancy outcomes"

## Healthy newborns

"Fewer babies born early or sick means better lifetime health and learning for populations"

## Equity

"The main drivers of health and wellbeing lie outside the health system"

## Climate & environment

"GenV must help limit global heating and its impacts for children, families and communities"

## Mental health

"The mental health of populations is critical to solving today's challenges"

## Healthy development

"We need scalable ways to assess and promote the best outcomes for brains and bodies"

## Allergy & immunity

"Reversing the rise in allergy – via prevention and cures – is the next frontier"

## Infection

"We need to reduce the harm from infectious diseases and antibiotics"

## Obesity & diabetes

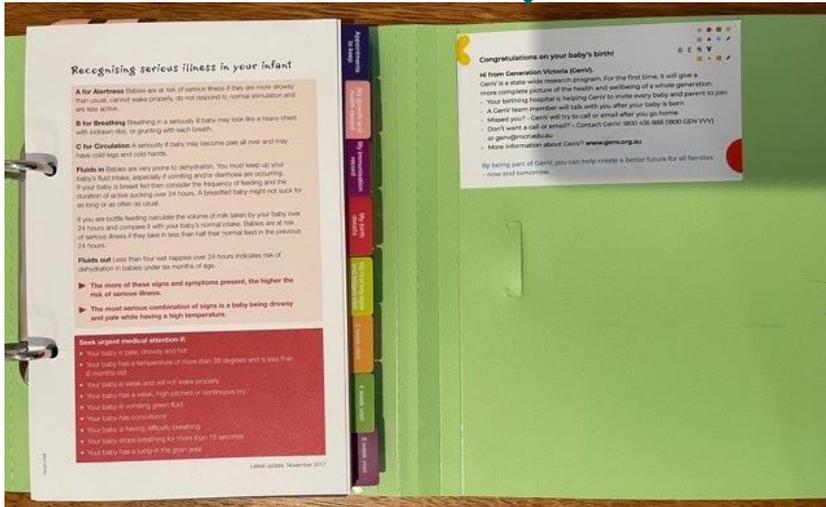
"Globally, one in five deaths are associated with poor diet"

## Population genomics

"How can we harness the power of genomics for all?"

# Green book MCH Nurse

This sticker is placed in all Green books in hospitals/from the printers mid-2022






**Congratulations on your baby's birth!**

**Hi from Generation Victoria (GenV).**

GenV is a state-wide research program. For the first time, it will give a more complete picture of the health and wellbeing of a whole generation.

- Your birthing hospital is helping GenV to invite every baby and parent to join
- A GenV team member will talk with you after your baby is born
- Missed you? - GenV will try to call or email after you go home
- Don't want a call or email? – Contact GenV: 1800 436 888 (1800 GEN VVV) or [genv@mcri.edu.au](mailto:genv@mcri.edu.au)
- More information about GenV? [www.genv.org.au](http://www.genv.org.au)

By being part of GenV, you can help create a better future for all families – now and tomorrow.

This sticker is placed in all participating families' Green book after they are recruited in person.



If they are recruited over the phone, this sticker won't be in their books but they are still part of GenV!

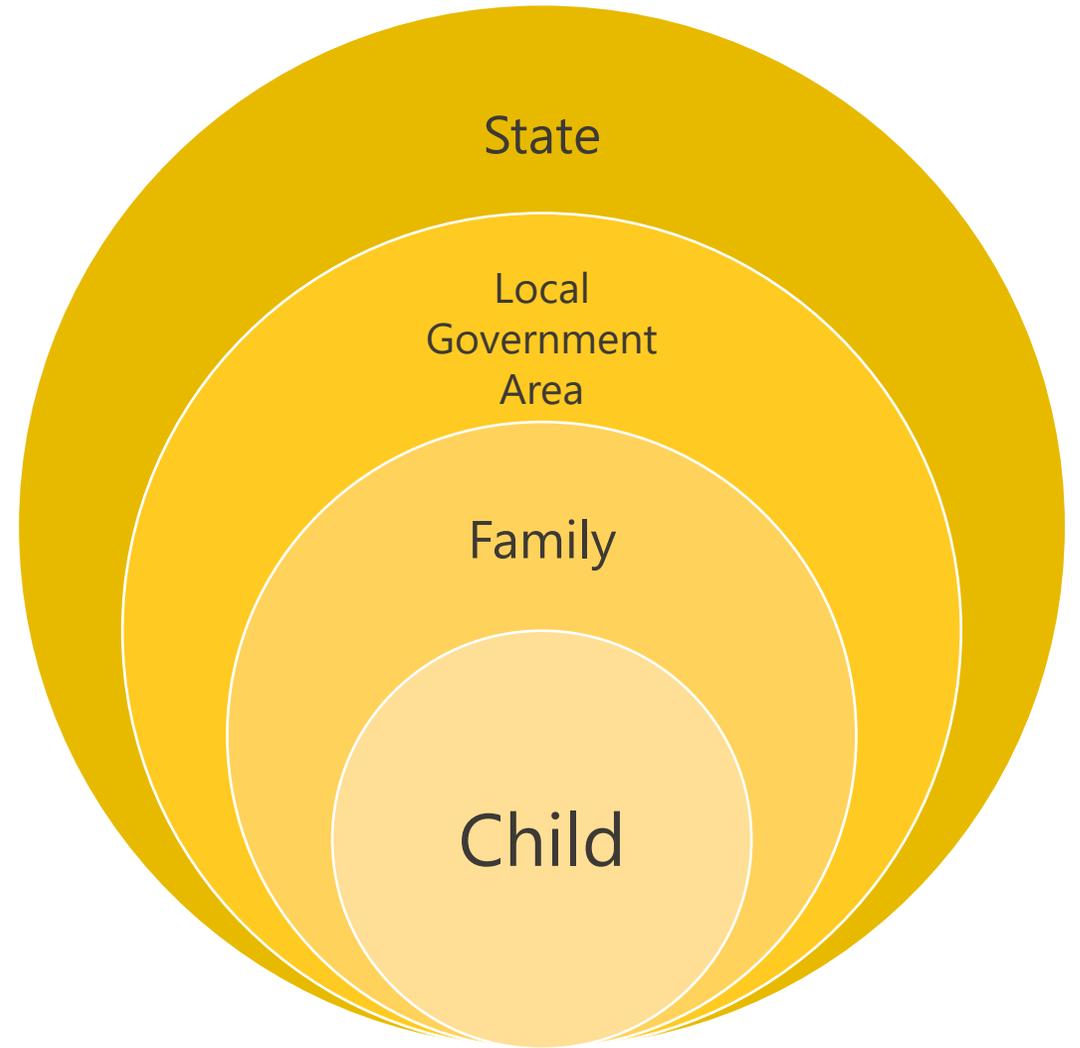
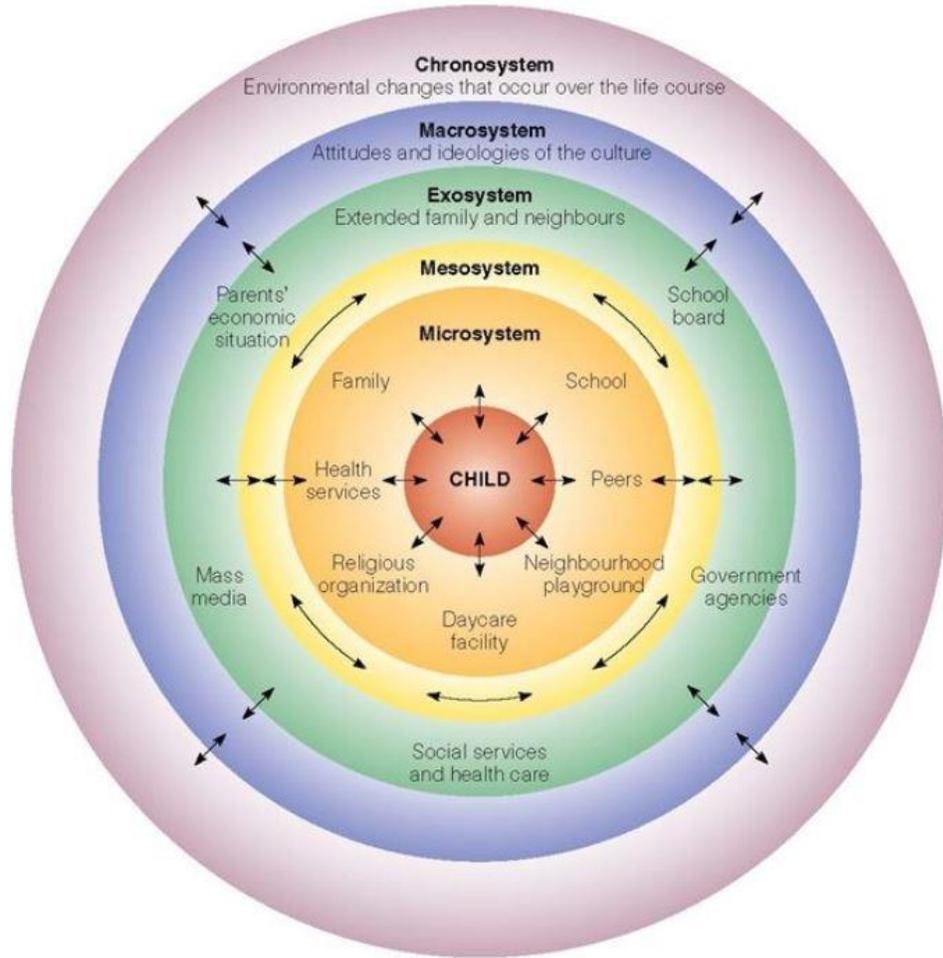




*"I'm a GenV Kid"*

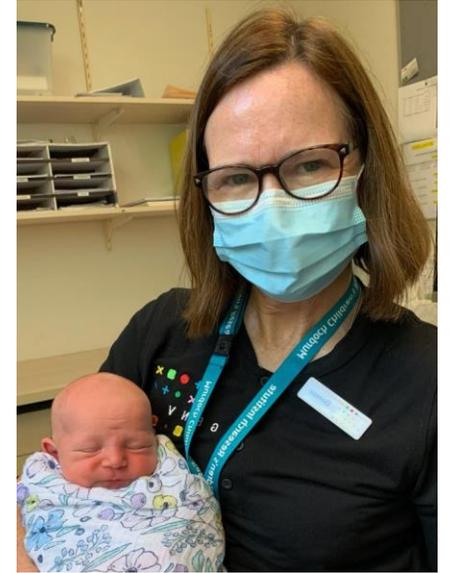
+ T:1800 436 888 E: [genv@mcri.edu.au](mailto:genv@mcri.edu.au) W: [genv.org.au](http://genv.org.au)

# Context of the child and their family

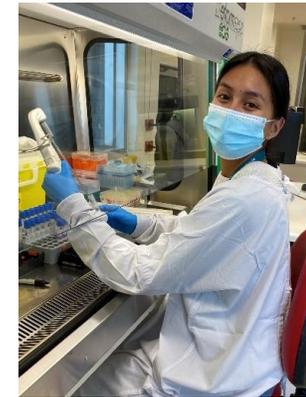


# GenV adding value to MCH Nurse Program

- GenV will provide additional information we've never had about parents and children
- Size and scale will provide a more complete picture of families
- Future benefit - observational and interventional research to drive practice/system change
  - A/Prof Valerie Sung research on cCMV will look at ways to prevent or enable earlier treatment for hearing loss through whole of population test



*Understanding the whole family will complement MCH Nurse Program data*



Many things we need can wait,  
the child cannot.  
Now is the time his bones are  
being formed, his blood is being  
made, his mind is being  
developed.  
To him we cannot say tomorrow,  
his name is today.

Gabriela Mistral  
(1889-1957)



**Historically, pandemics have forced humans to break with the past and imagine their world anew. This one is no different. It is a portal, a gateway between one world and the next. We can choose to walk through it, dragging the carcasses of our prejudice and hatred, our avarice, our data banks and dead ideas, our dead rivers and smoky skies behind us. Or we can walk through lightly, with little luggage, ready to imagine another world. And ready to fight for it.**

Suzanna Arundhati Roy



# Thank You

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[www.genv.org.au](http://www.genv.org.au)

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# Q & A

