

Melbourne
Children's

The Royal
Children's
Hospital
Melbourne



Murdoch
Childrens
Research
Institute



THE UNIVERSITY OF
MELBOURNE



Generation Victoria – Gen V

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Victorian Infant Hearing Screening Program



- Statewide screening in Victoria, Australia
- Commenced in 2005, rolled out 2008 - 2012
- ~ 78,000 screened babies annually
- 98.8% of eligible babies screened
- KPI >97% screened by 1 month corrected
- ~1% refer rate
- detection rate ~1.0 per 1000
- Administered centrally through RCH

Happy Birthday VIHSP



Purpose of VIHSP



To improve language, health and quality of life outcomes for children and families by

- providing high-quality universal newborn hearing screening
- educating families and practitioners about hearing health
- enabling research

Melbourne Children's



- Royal Children's Hospital – major specialist hospital in Victoria
- Murdoch Childrens Research Institute - preeminent child health research institute in Australia
- University of Melbourne – Department of Paediatrics co-located at RCH



The Big Idea →



Generation Victoria

Transforming the health and well-being of generations of children



Gen V – The Platform



1. **Recruitment** of babies born in Victoria in 2 calendar years (80,000/year)
 - a) Collection of biological specimens
 - b) Surveillance of health and development and episodes of care
2. **Biological specimens** (subsets with deep and serial measures)
3. **Linkage** to State and Federal datasets.
4. **Repository of clinical information** on attending clinical services across the whole continuum of care community → primary → secondary → tertiary care. E.g. capture data from RCH's admissions, surgeries, emergency presentations, and outpatient visits.
5. **GIS capability** to allow geographic (both environmental and spatial epidemiology), place-based, health economic and health services research.

Goals



1. To generate high impact scientific outcomes that translate to improved childhood health in Victoria, Australia and ultimately, globally;
2. To generate a unique resource for knowledge creation in child health;
3. To provide a platform to bring the public, researchers, clinicians, service providers and policy makers together to focus on the challenges of child and adolescent health;
4. To foster collaboration amongst these diverse stakeholder groups to increase efficiencies in healthcare and maximise clinical outcomes.

What questions can Gen V answer?



Obesity and
Cardiovascular
Disease



What questions can Gen V answer?



Obesity and
Cardiovascular
Disease

Causal
pathways to
early growth
trajectories
and infant
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Allergy &
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Causes,
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Infection and
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Patterns and
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Neurodevelopment

The ideal
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Mental Health

The avoidable
burden of
inequity on
parent and
infant wellbeing
in the first year
of life

What are the blocks that Gen V could fix?



The current situation:

- Excellent but disconnected research
- Excellent but poorly coordinated health care services and systems
- Huge research waste – each new project:
 - ~~must be set up from scratch~~
 - ~~must collect its own outcomes~~
 - ~~can last only as long as its funding, usually 3-5 years~~
 - ~~inevitably loses many participants~~
- An incomplete picture of the factors that influence health and well-being of individuals and communities

The ideal: A powerful platform uniting research, practice and policy with a shared language



Generation Victoria aims to create this platform, working with and across the whole of Victoria

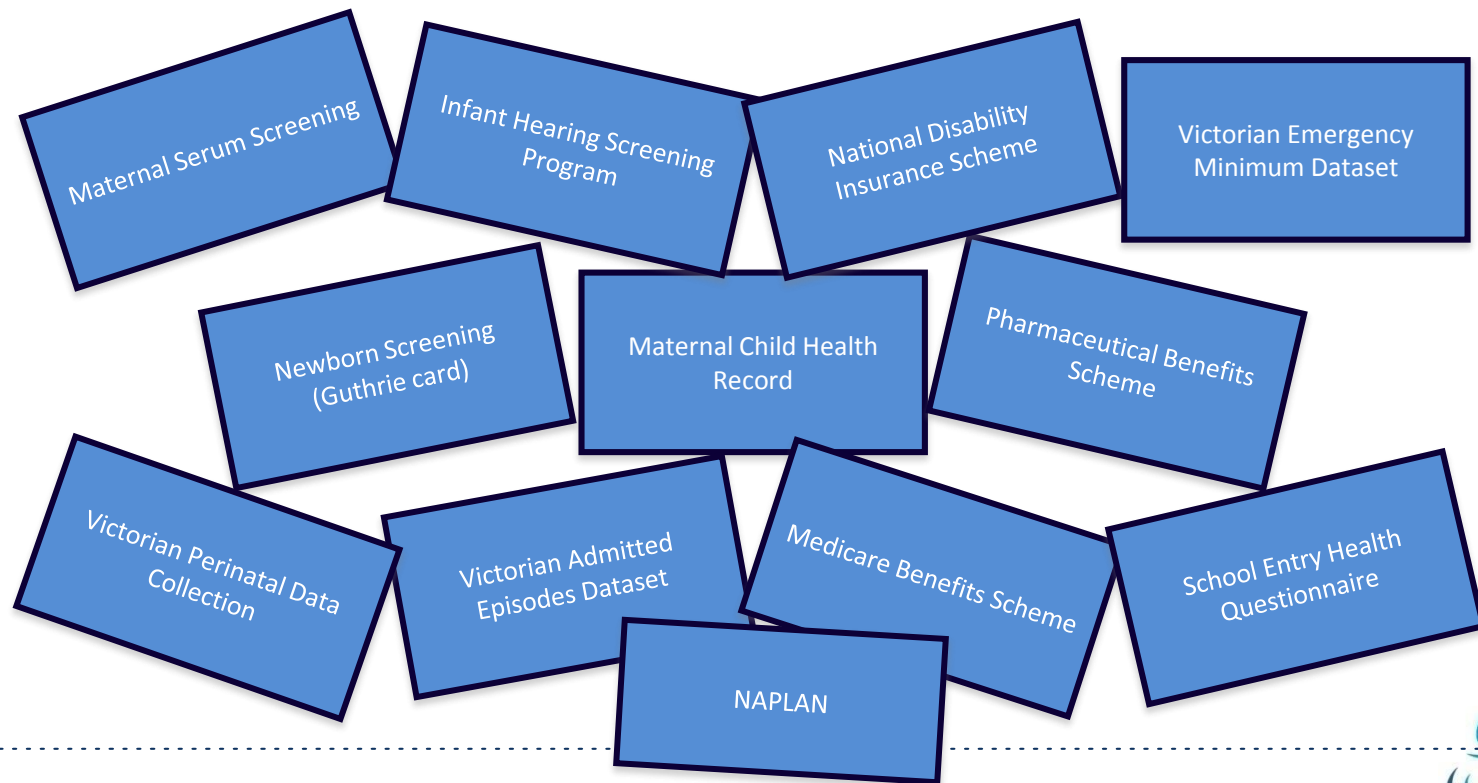
It is a new research system designed to address many of today's pressing problems

It is built on connecting and linking the information that governments, clinicians and services already collect

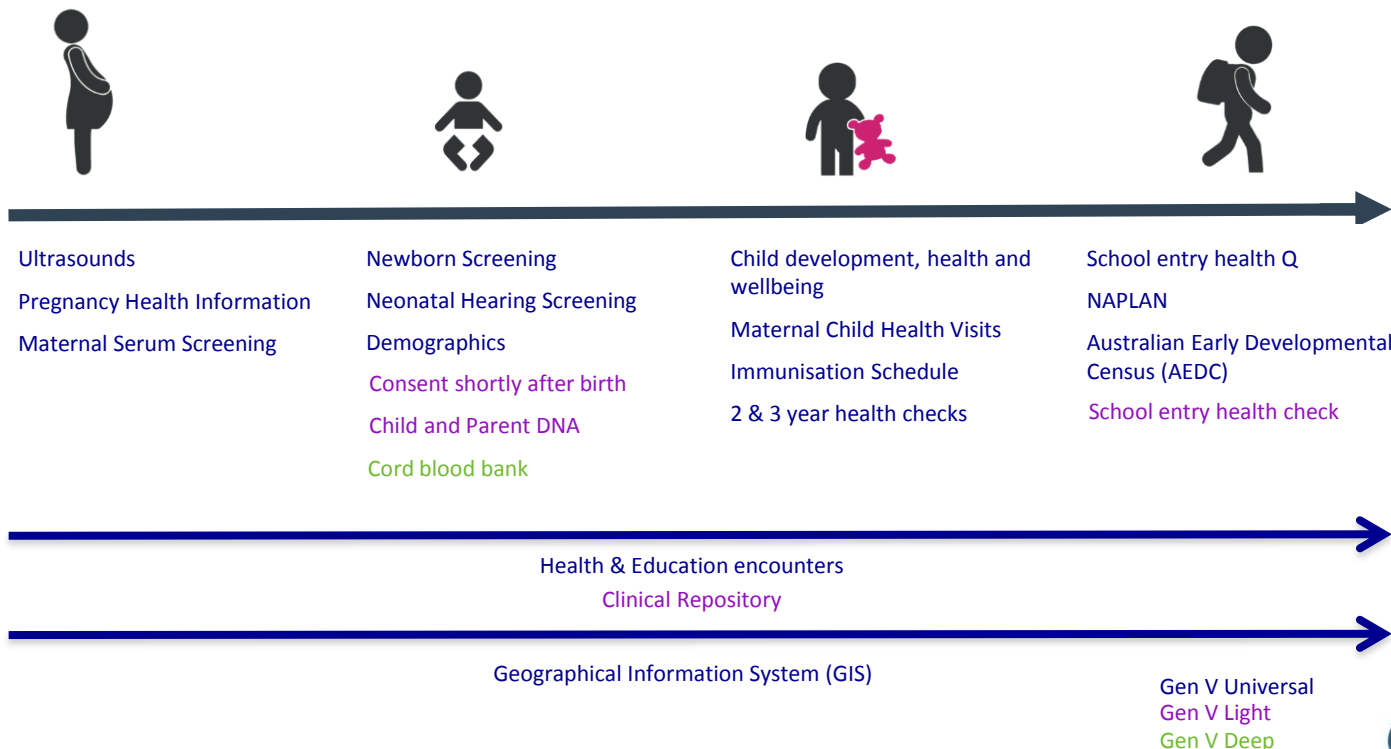
It is built on the best science and the best practice

It will be timely, efficient, and drastically cut down waste

The possibilities



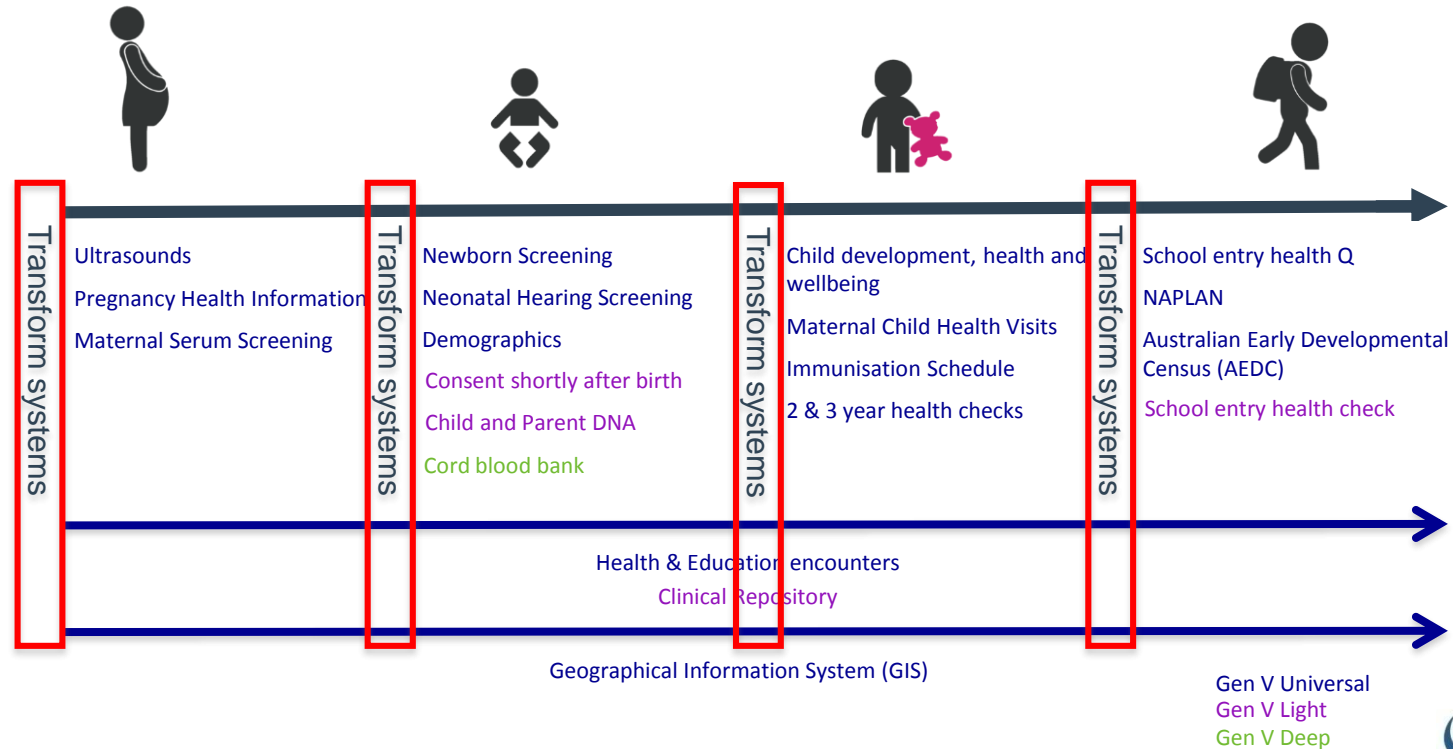
Linking biology, services and population health



Gen V Universal
Gen V Light
Gen V Deep



Powerful transformation, minimal change, manageable speed



Why involve VIHSP?



- Single managing organisation for hearing screening in whole state,
- Easiest/most efficient (time, cost, age of baby) way to reach a teamed workforce to identify participants as close as possible to birth
- Well established infrastructure for capture
- Real-time tracking of births and transfers – only system that covers all births within days

VIHSP



- Work with all 77 birthing centres

coverage:

- 96.3% of births within 5 days
- 99.2% of births within 30 days
- Nearly all screened in hospital prior to discharge
- Inpatient and outpatient mechanisms
- Tracking of infants in near real-time (only system in the state that does this!)
- highly cost efficient
- Systems developed for consent and screening of all groups within the population



The Phase 1 Pilot Study - AIMS



1. Feasibility of conducting the Gen V interview after the VIHSP hearing screen
2. Gen V questionnaire administration and item feasibility
3. Biospecimen collection, transport, processing and storage procedures feasibility
4. What parents think about the Gen V recruitment and Gen V study processes involved
5. Process and outcome evaluation of the impact, if any, of the Phase 1 pilot study recruitment on the VIHSP hearing screen.
6. Process, Resource and management requirements for the planned Gen V recruitment process to inform future piloting.



The Phase 1 Pilot Study

60 families:

- child, mother/parent 1 and father/parent 2 (no siblings)
- one tertiary maternity hospital

What does participation involve for families?

Participation in this pilot study takes roughly 20 minutes, plus the time it takes to explain, consent and recruit families

- A brief questionnaire
- A saliva sample from baby, mother and father
- A short feedback form

What's involved for VIHSP



1. Help Gen V recruiters to identify eligible families on the ward (at the start of the day)
2. Hand out a Gen V postcard to eligible families (after screening has commenced)
3. Ask (using script) if families are happy to be introduced to the Gen V recruiter
 - If yes, then bring Gen V recruiter into room & introduce family
 - If no, ask family if they want to fill out a Non- Responder form (~3min).

What's in it for VIHSP



- Promoting one of the VIHSP-identified purposes and priority areas
- Helping to advance health care knowledge and services



Preliminary Results

- 88% of families said yes to Gen V approach
- Reason's why not:
 - (6) no reason given
 - (7) too busy/overwhelmed
 - (3) not interested in research
 - (2) found to be ineligible
 - (1) being discharged



Reasons for not taking part (now)

- (43) Time: → approach through mop up mechanism
 - 19 being discharged, 14 too overwhelmed, 7 time poor/too busy, 3 too much on with first baby
- (15) Tired/recovery from birth: → approach through mop up mechanism
 - 7 tired, 4 traumatic delivery/in pain, 2 mother not feeling well, 2 recovery from Caesarian Section
- (15) Research based: → provide further information prior to approach
 - 4 Worried about privacy or confidentiality, 4 one parent interested and other not, 3 uncomfortable with samples being collected, 2 Not interested in research, 2 in other research already
- (4) Language/found to be ineligible → use VIHSP developed processes
- (3) Breastfeeding issues → approach through mop up mechanism

Consents



n (%)		Child	Mother	Father	Comments
Enrolled	Yes	60	59 (98%)	46 (77%)	Of those fathers asked 9/10 yes
	No			5 (8%)	
	Follow-up			6 (10%)	
	NA		1 (2%)	3 (5%)	Not eligible, not available, etc.
Saliva		54 (90%)	53 (90%)	42 (91%)	
MSS		-	57 (97%)	-	
Guthrie	Yes	57 (95%)	41 (69.5%)	34 (74%)	Of those born in Australia: 89% of mothers 96% of fathers
	No	3 (5%)	5 (8.5%)	1 (2%)	
	NA		13 (22%)	11 (24%)	Born outside of Australia



Parent feedback

	Mean	Mode	Min	Max
I thought the Information Statement & Consent Forms were easy to understand	4.8	5	4	5
I thought the information provided to me about the study was sufficient	4.8	5	4	5
I thought the length of time used to explain the study was sufficient	4.75	5	4	5
I thought the questionnaire was easy to understand	4.25	4	3	5
I thought the length of time it took to complete the questionnaire was satisfactory	3.56	5	1	5
I felt comfortable with the researchers collecting and storing my child's cheek swab	4.8	5	4	5
I felt comfortable with the researchers collecting and storing my cheek swab	4.8	5	4	5
I thought the total length of time it took to participate in this research project was satisfactory	4	4	2	5
Overall I am satisfied with my experience participating in the Gen V Pilot Study	4.5	5	3	5



Impact on VIHSP

- No missed screens over recruitment time
- VIHSP staff have picked up introduction easily, have been very helpful and have not had any complaints

	Mean	Min	Max
Introduction time (min)	1.6	1	3.5

- No obvious impacts on VIHSP staff (feedback to VIHSP management and Gen V team)

Pilot Learning thus far



- We can successfully complete the Gen V interview after VIHSP
- Need to shorten our questionnaire and interview process
- Better ways to make the consent form shorter
- Certain groups, e.g. Caesarean section will possibly need to be approached later than the VIHSP screen
- Cost and budgeting for next phases of piloting recruitment, including:
 - Prenatal information to all pregnancies
 - Both opt-in and opt-out consent
 - Full coverage and approach to all births (no exclusion criteria)
 - inpatient and outpatient recruitment
 - Post maternity hospital recruitment



Next steps in analysis

- What times of day were the most successful for approach?
- What were the differences in response rates and completion times between different groups of the population?
- More detailed analysis for groups we need to design outpatient recruitment approaches for?

Making it happen



2013

- Coalition of researchers and clinicians
- International and national benchmarking
- State and federal data mapping
- Gen V design development

2014

- Ethics engagement
- Systems development pilots
- Maternity hospital and pathology provider engagement

2015

- Generation Victoria feasibility pilots
- Links with Victorian services (e.g. maternity hospitals, Maternal & Child Health Services)
- MCRI, RCH, UoM investment (funds + in-kind)
- MCRI, RCH and UoM will seek philanthropic and government funding

2016

- Dedicated Gen V Director and Hub Leaders
- Systems development and implementation
- Generation Victoria Vanguard study

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