



Norwegian Mother & Child Cohort Study - Norway

105,422

ALSPAC - UK

14,541

Danish National Birth Cohort - Denmark

96,840

National Children's Study - USA

100,000

Sino-US CPBDDP - China

245,000

Tasmanian Infant Health Survey - Australia

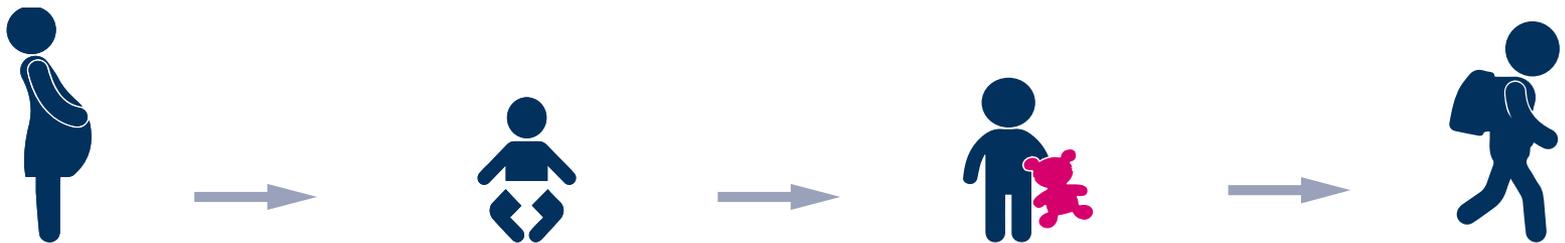
10,627





What is Gen V?

Research at the heart of a connected infrastructure of world-leading health and education services



| | | | |
|--|---|---|---|
| <p>Ultrasounds</p> <p>Maternal Serum Screening</p> <p>Birthing Outcomes System</p> | <p>Newborn Screening</p> <p>Infant Hearing Screening</p> <p>Consent soon after birth</p> <p>Child and Parent DNA</p> <p>Cord blood bank</p> | <p>Maternal & Child Health Visits</p> <p>Immunisation Register</p> <p>Brain Development</p> | <p>School Entrant Health Q</p> <p>Australian Early Development Census (AEDC)</p> <p>NAPLAN</p> <p>Victorian Student H&WB Survey</p> <p>School health checks</p> |
|--|---|---|---|

Health & Education service encounters: Administrative Data (e.g. VAED, VEMD, Medicare)

Clinical & Developmental Repository

Geographic Information System (GIS)

Existing but joined-up collections
 Gen V Specific



Gen V – The Platform

1. Statewide Recruitment from live births in Victoria over 2 calendar years (80,000/year)* with longitudinal surveillance of health, development and episodes of care.
2. Collection of biological specimens
3. Consented Linkage to State and Federal datasets.
4. Establishment of a repository of clinical information on children attending health services across the primary, secondary and tertiary care sectors. This will encompass data linkage of biospecimen and clinical outcome measures.
5. Geographical Information System (GIS) data of geographic (both environmental and spatial epidemiology), place-based, health economic and health services origin.

Biospecimens

1. Maternal serum sample collected as part of routine statewide screening program on >80% of pregnancies (~60,000 per annum)
 - taken between 9-12 weeks gestation.
 - Store remaining serum and clot
2. Cord blood collected as part of routine clinical care on up to 20,000 births across 3-5 hospitals.
3. Guthrie Card collected as part of routine statewide screening program. 1 full spot (up to 9 punches) biobanked at -80°C on all births
4. Saliva sample shortly after birth on:
 - Mother
 - Father
 - Newborn

Further depth collections as part of investigator initiated nested sub-studies

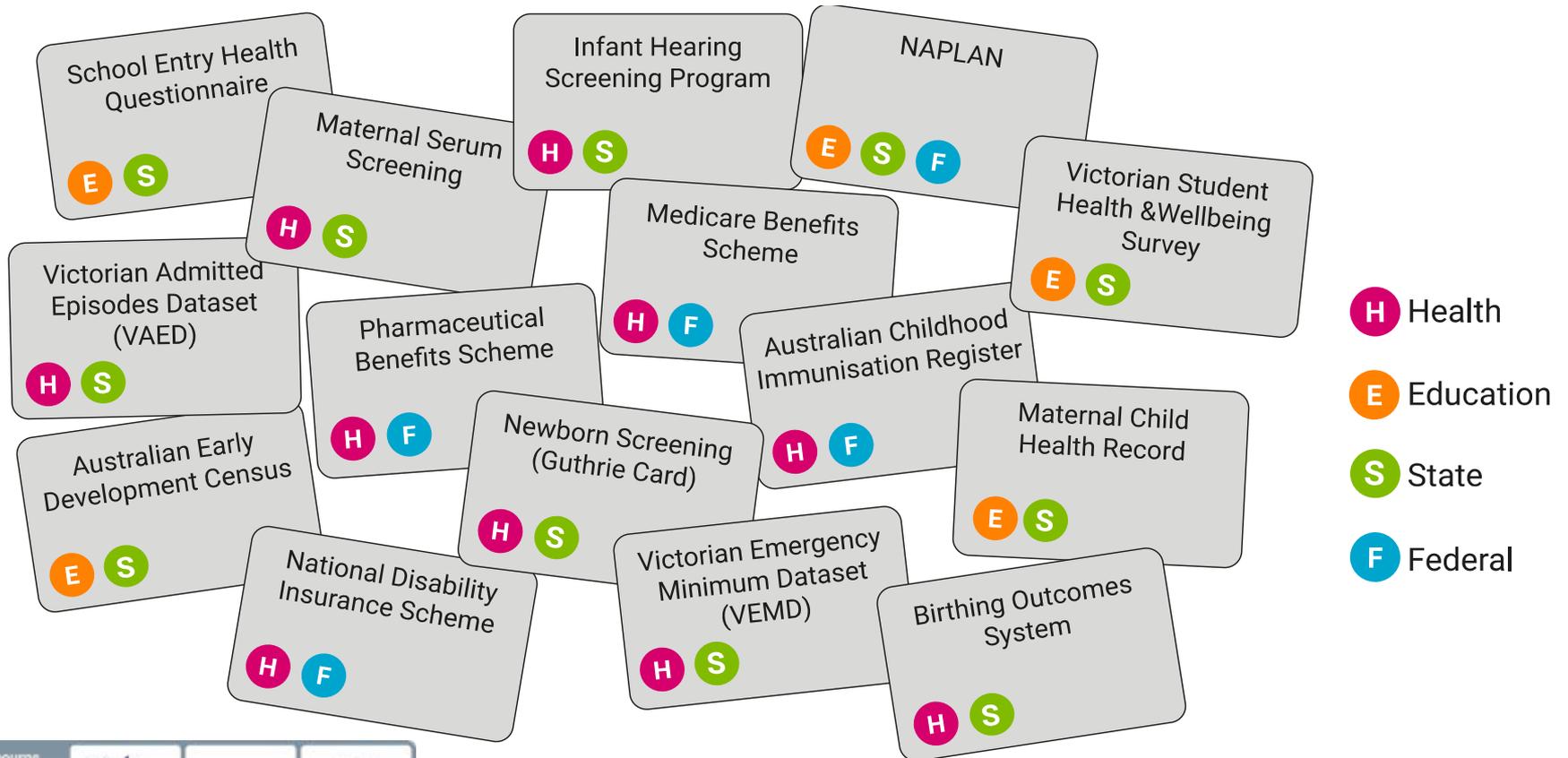


Progress

1. A large collaboration of people working towards a single goal
2. International Benchmarking complete
 1. Funding Pilot studies to demonstrate feasibility:
 - Focus groups with expectant parents (complete)
 - Recruitment pilots
 - Biospecimen pilots (Cord blood collection and prenatal maternal serum)
 2. Engaged with many groups
 - Still more to do
 - Very positive feedback so far

Current Situation

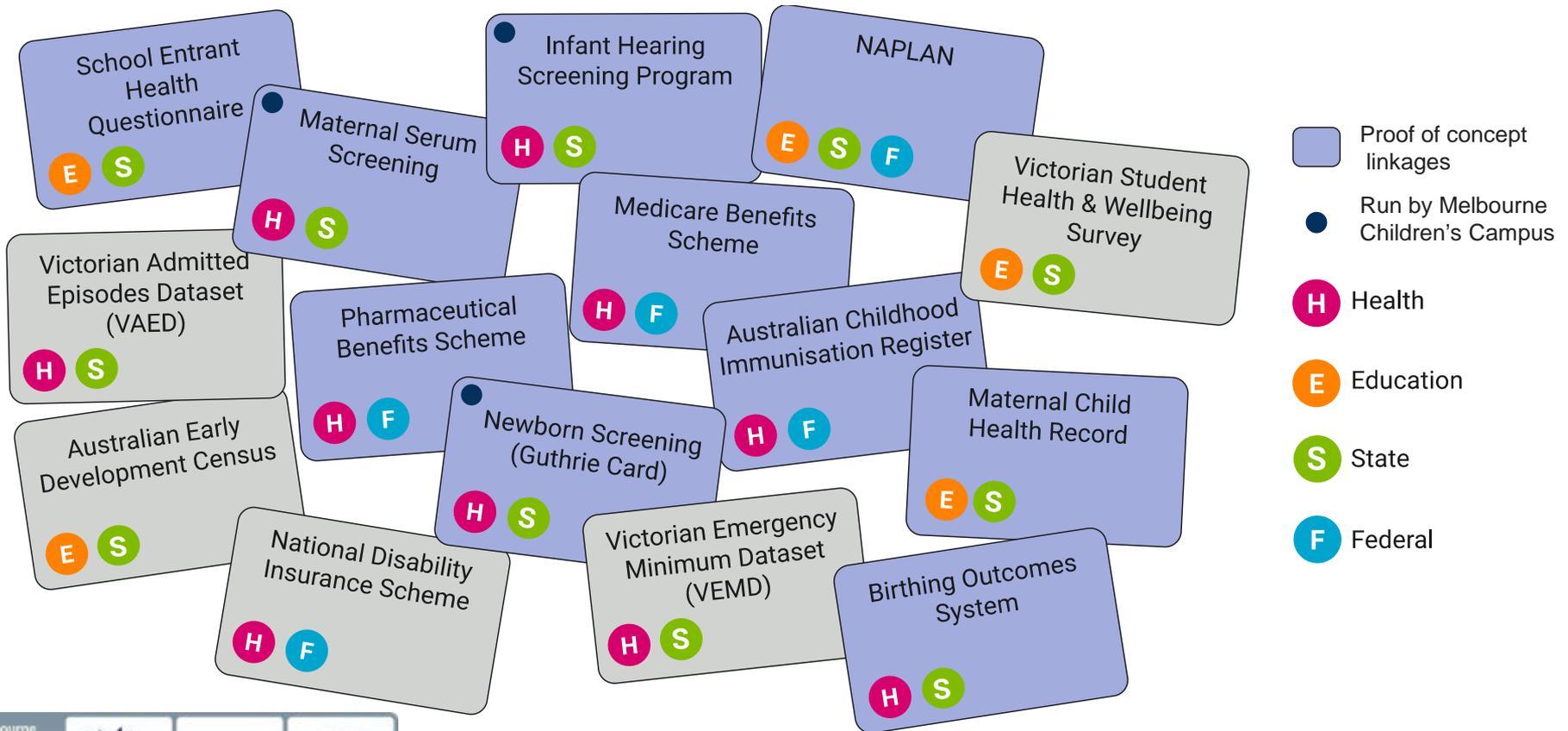
Excellent but unconnected state-wide services/datasets, on which billions of dollars are spent annually





Current Situation

Excellent but unconnected state-wide services/datasets, on which billions of dollars are spent annually



Gen V – The Platform

- 1. Recruitment** of all babies born in Victoria in 2 calendar years (76,000/year*)
 - Surveillance of health and development and episodes of care
- 2. Biological specimens**-whole of State- maternal serum screening (approx. 80%, archived neonatal blood spots, approx. 99.6%, deep sub component (n=5 metro hospitals in Capital city, funding dependent; cord blood. Nested case control studies- blood on incident cases and aged controls within Gen V birth years as cases occur.
- 3. Linkage** to State and Federal datasets.
- 4. Repository of clinical information** on children attending health services
 - Capture data of admissions, surgeries, emergency presentations, and outpatient visits and cancer.
- 5. GIS capability** to allow geographic (both environmental and spatial epidemiology), place-based, health economic and health services research.

Collaborative Group Processes

- Need to explicitly consider collaborative processes and design for success (Mattingly & Ponsonby. Ann Epidemiol. In Press)

| Purpose | Considerations | |
|----------------------------------|--|---|
| Purpose | Information gathering | High cognitive diversity ,crowd sourcing |
| | Highly merged cognitive work | smaller groups with greater communication |
| Communication | Face-to-face, video conferences, teleconference, email and Yammer | |
| Size | Reflects cognitive diversity required, communication limits, nature of task and overall structures | |
| Members | Choice of correct members and leaders (expertise and interpersonal styles), incentives and disincentives | |
| Decision making | Structure and protocols for decision making, awareness, normative interventions, Delphi approach | |
| Overall organisational Structure | Multilevel groups, consider context, organisational management theory, Agile project management | |

The strategy: making it happen



Phase 1: Investigation

Transforming data systems

- Scope existing datasets to determine data logistic, IT and legislative barriers and find solutions
- Consult with data custodians to determine most efficient data transfer processes
- Intersect with existing projects and policy to ensure existing processes are informed and maximised
- Test consented data linkage processes with existing MCRI datasets in its LifeCourse Repository
- Establish, test and cost new data collections and biobanking processes

Phase 2: Implementation

The Gen V Cohort

- Apply these new processes to prenatal samples and imaging
- The Gen V cohort: consented data collection begins soon after birth, including existing and new data collections
- Implement staged database/service modifications as a vanguard strategy at least 1 year ahead
- Engage Victorian researchers, policymakers and practitioners
- Use early Gen V data to address key questions spanning pregnancy and the first year of life

Phase 3: Sustainability

Creating the legacy

- Embed redesigned data collections into existing systems with service and policy commitment
- Build ongoing consented data linkage approaches that maximise the utility of all data collected
- Design low cost processes for research and service data access

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

Gen V aims to create this platform, working with and across an entire population

Children at the heart – problems of ageing the end game

Connects and links the information that governments, clinicians and services already collect

Built on the best science and the best practice

Timely, efficient, and drastically cuts down waste

Thank you

Melbourne
Children's
Excellence in
clinical care,
research and
education

