# GenV Focus Area Survey Final Report


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## Publication date

September, 2020

## Series Number

2020-04



## Abstract

The GenV Focus Area Survey was developed to engage with policymakers, researchers and practitioners in order to road test its six proposed Focus Areas and to ensure that GenV was developing an inclusive data platform that could meet the needs of a wide range of users. An online survey was conducted and found that mental health and wellbeing (particularly mothers' and babies') were the most important priorities. The diversity of interests align with GenV's Lifecourse approach.



## Keywords

Content Areas, Priorities, Consultation, Cross-sectional survey, Cohort, Design, GenV

## Citation

Lauren Davenport, Naomi Schwarz, Jing Wang, Yanhong Jessika Hu, Melissa Wake, Sharon Goldfeld (2020). GenV Focus Area Survey Final Report. *Generation Victoria Working Paper 2020-04*. DOI:10.25374/MCRI.13003985


## Aboriginal acknowledgement

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

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# Acknowledgement

This report is a collaborative effort. We wish to express our appreciation of the vital contributions made to this project by the policymakers, researchers and practitioners in helping to shape GenV's priorities by identifying unanswered questions within the GenV Focus Areas.


# List of abbreviations & glossary

| | |
|---|---|
| ANZSOG | Australian and New Zealand School of Government |
| ARACY | Australian Research Alliance for Children and Youth |
| CHA | Children's Healthcare Australasia |
| GenV | Generation Victoria |
| MCC | Melbourne Children's Campus (MCRI, RCH, The University of Melbourne) |
| MCRI | Murdoch Children's Research Institute |
| RACP | The Royal Australasian College of Physicians – Paediatrics and Child Health Division |
| RCH | The Royal Children's Hospital, Melbourne |
| WHA | Women's Healthcare Australasia |

# 1. Executive Summary

Generation Victoria (GenV) is the largest birth cohort study ever planned in Australia (n>100,000). Its primary objective is to create very large, whole-of-state birth and parent parallel cohorts for discovery and interventional research that accelerate research to improve the health of children and their families. To achieve this objective, GenV needs to focus on outcomes that are important to families, services and policymakers and supports research that maximises the benefit of a large birth cohort.

GenV Focus Areas

GenV has developed a Focus Area Framework to summarise the six defined areas that broadly impact on children, parents and families (Figure 1). This framework considers 'Inequity and Vulnerability' across all focus areas, and initially concentrates on the 'Mothers and Babies' life stage.[1] The six areas encompass child and parent biology, physical and mental health, and the built and social environments in which children and their families live, work and play.

**Figure 1:** Focus Areas

GenV Focus Area Survey

The GenV Focus Area Survey was developed to engage with policymakers, researchers and practitioners, to road test the six proposed Focus Areas and to ensure that GenV was developing a data platform that could meet the needs of a wide range of users.

An online REDCap survey was sent to practitioners, service providers/managers, researchers, policymakers and project managers through GenV's partners and some peak bodies between September and November 2019. Respondents were asked which focus area was most relevant to their work. They were then asked to think about the focus area in relation to the first 1000 days of a children's life and the top three priorities needing solutions within the focus area. Statistical analyses were performed in Stata V.15.0.

Results

A total of 176 participants responded to the survey; they comprised a broad range of users.

Respondents worked across different sectors but predominantly the health sector (77 per cent). The work of most respondents was based in the state of Victoria (n=66), but all states and territories were

represented.

- The top two priorities nominated by respondents related to mental health and wellbeing in families, specifically mothers and babies.
- This was followed by priorities related to early childhood development and education, environmental factors impacting on health, prevention of childhood obesity, and access and engagement with services.

Discussion

There were two key findings:

1. **The diversity of the top five priorities**
2. **Top priorities were similar across sectors and primary roles.**

The top five priorities reflect some of the complex issues of our time but they also reflect the complex interplay between the individual, their family, their community and society more broadly. The diversity of interests across health and education is well reflected and aligned with GenV's Lifecourse approach. The fact that these issues were identified across sectors supports the breadth of GenV and highlights the need for multi-disciplinary and multi-sector approaches to help solve these complex issues.

The survey's findings have implications for GenV's data collection and engagement across sectors. One of the purposes of conducting this survey was to find out what priorities were important to our users so GenV can collect data that addresses them. The challenge for GenV will be how we collect data on these five broad priorities, including the top priority of mental health, to meet the needs of our users.

Addressing complex issues requires working together across sectors focused on a common goal. An important role and principle of GenV is to ensure there is high quality data that can facilitate these collaborations and partnerships to help solve the complex issues affecting today's children and adults. These key findings will inform future work with researchers, practitioners and policymakers.

Strengths and limitations

- **Limitation:** By design, the sample was not representative, so the priorities listed by respondents were unlikely to be representative of the general population. Respondents worked predominantly in the health sector (77 per cent).
- **Strength:** The survey successfully engaged a relatively large number of diverse respondents working across sectors, states and primary roles (n=176).

Conclusion

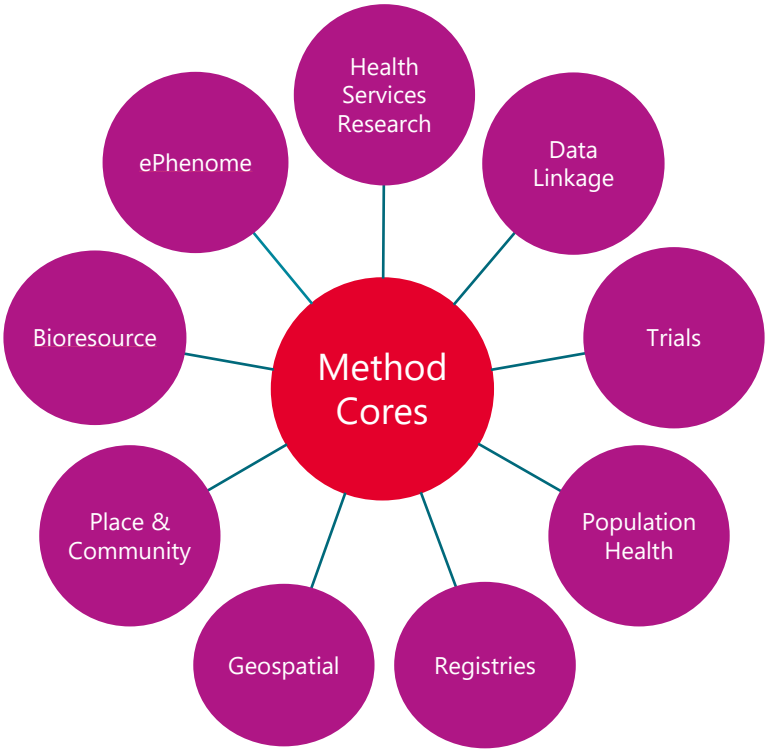
The Focus Area Survey was an important element of GenV's initial engagement with a large number of researchers, practitioners and policymakers across sectors and states. This report finds that families' mental health and wellbeing (particularly that of mothers and babies) was the most important priority identified. The diversity of interests across health and education is well reflected and aligned with GenV's Lifecourse approach.

# 2. Introduction

Children's health, so vital to Australia's future prosperity, may be declining. Over the last 30 years, many childhood problems (such as autism, coeliac disease, obesity, allergy, mental health) have worsened, with long-term consequences for ageing societies. Studies of more than 100,000 participants, known as mega-cohorts, have transformed later-life discovery, translation and commercialisation internationally. However, research is not keeping pace with need. A major block is the laborious, slow and costly nature of research participant assessments.

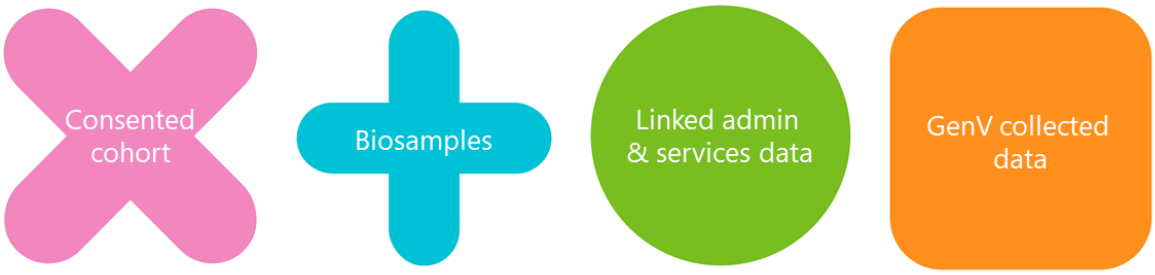
Generation Victoria (GenV*)* is the largest birth cohort ever planned in Australia (n>100,000). Its primary objective is to create very large, parallel whole-of-state birth and parent cohorts for discovery and interventional research that accelerate research to improve the health of children and their families. To achieve this objective, GenV needs to focus on outcomes that are important to families, services and policymakers and support research that maximises a large birth cohort. GenV is working with our partners and users to focus on the scientific methodological approaches required to deliver different types of research in the Method Cores (Figure 2) and the exposures and outcomes in the content driven Focus Areas. Within a single cohort framework, GenV's Method Cores and Focus Areas drive diverse capability, content and collaboration.

**Figure 2:** Method Cores




GenV will recruit for two full years from 2021 in all of Victoria's 70 birthing hospitals, in which collectively around 80,000 babies are born each year. All children born in Victoria during the recruitment period and their parents, are eligible to take part. The cohort design comprises four elements (Figure 3).

**Figure 3:** Cohort Design




The main cohort is planned to begin in 2021, preceded by a Vanguard in 2020. Its Vanguard Protocol is approved by The Royal Children's Hospital HREC (2019.011), which has also broadly endorsed the approach for the main cohort.

## 2.1 GenV Focus Areas

GenV has developed a Focus Area Framework (Figure 4) to summarise the six defined areas that broadly impact on children, parents and families. This framework considers 'Inequity and Vulnerability' across all focus areas, and initially concentrates on the 'Mothers and Babies' life stage.[1] The six areas encompass child and parent biology, physical and mental health, and the built and social environments in which children and their families live, work and play. When overlaid with inequity,[2] the focus areas and the interaction between them, encompass many of the complex problems affecting children today.[3,4] If not prevented or solved, complex childhood disease can become chronic diseases in adulthood and impact children's health, social and economic life outcomes.[5] These areas are not intended to be exclusive but rather to assist GenV in engaging with users and in planning a useful and robust data collection.

**Figure 4:** Focus Areas

Each Focus Area is summarised in Figure 5 and further details of each Focus Area can be found in Appendix A.

**Figure 5:** Summary of Focus Areas

- **Mental Health & Wellbeing** [6]
  Social and emotional wellbeing throughout life to support resilience and mental health
- **Development & Learning** [7]
  Pathways that can build the foundation for lifelong development and learning
- **Infection, Immunity & Allergy** [8,9]
  Reducing allergy and immune disorders through effective prevention strategies and clinical care
- **Obesity & Diabetes** [5]
  Behaviours and mechanisms that provide a foundation for future health
- **Organ Health** [10]
  All body systems on their healthiest trajectory and free of disease, eg cardiovascular, gut, bone, lung, hearing, vision and oral health
- **Healthy Environments** [4,11]
  Healthy family, built and social environments
- **Mothers & Babies** [12]
  Healthy pregnancy and early years ensure the best lifelong outcomes for parents and children
- **Inequity** [2]
  Inequity is the presence of systematic and potentially remediable differences among population groups defined socially, economically or geographically

## 2.2 Purpose of the survey

GenV's aim is to galvanise researchers, policymakers, practitioners and service providers to develop new ways to study, prevent and solve problems in each of the focus areas. The GenV Focus Area Survey was developed to engage with our users, road test the Focus Areas and to ensure that GenV was developing an inclusive data platform that could meet the needs of a wide range of users. The survey aim was to both enable stakeholders to suggest their priorities and unanswered questions within the focus areas, and to stimulate thinking about GenV's role in answering questions that might otherwise not be possible.

# 3. Methods

## 3.1 Participants

The survey was initially distributed to practitioners, service providers/managers, researchers, policymakers and project managers through a limited set of peak bodies (RACP, CHA, ANZSOG, WHA, ARACY) with further distribution through their members. In addition, the GenV operations team, Investigator Committee and members of all established GenV Method Core and Focus Area Working Groups at the time (Newborns, Pregnancy, Optimising Antibiotics, Health Services, Trials, Registries, Population Health, Bioresources, Geospatial) were included. Invitations were emailed to all potential respondents and notices were posted on the MCRI news page, GenV's Twitter account, the GenV website and in peak body newsletters (Appendix B). Respondents were encouraged to forward the survey link to other parties who would be interested in completing the survey.

## 3.2 Survey

In order to encourage high response rates, the survey was very short. An online REDCap survey was developed containing basic demographic questions, including sector, primary role and in which state their work was based (see Appendix C). Respondents were asked which focus area was most relevant to their work. They were then asked to think about the focus area in relation to the first 1000 days of a child's life and the top three priorities needing solutions within the focus area. These were then scored as described in the Data Analysis section. Respondents were asked to list any datasets they knew of that would be relevant to understanding, investigating, evaluating and reporting on their top priority. Respondents were also given the opportunity to select another focus area that was relevant to their work in case they worked across more than one focus area. If they did, they were also asked to fill out the priority areas and list relevant datasets for the second focus area.

Finally, respondents were given the opportunity to comment in their own words on the priority area/s they listed. The survey was open from 9 September until 18 November 2019.

## 3.3 Data analysis

Statistical analyses were performed in Stata V.15.0. We used descriptive statistics to describe the sample characteristics and the priorities within each focus area. All categorised variables were described as frequencies and percentages. To understand the priorities put forward by our respondents we ranked priorities using a weighted scoring method. For each priority area, we awarded 3, 2 and 1 point if it was nominated as the first, second and third priority, respectively. Next, we multiplied the number of votes by the point. Last, the total score was calculated for each priority area by adding up the priority scores for each priority area, with higher scores indicating higher priority. We ranked the priority areas within each focus area according to the total score. We further described the ranking results by primary role of the respondent and by sector.

# 4. Results

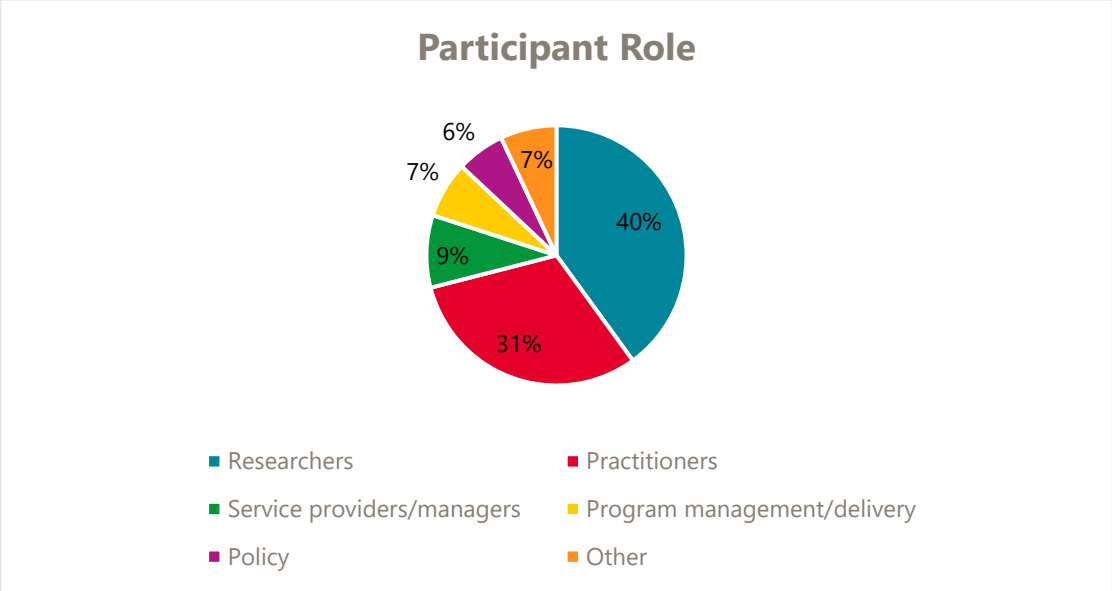
## 4.1 Respondents

A total of 176 participants responded to the survey; they comprised a broad range of users. Although they were mainly researchers and practitioners (71 per cent), they also included service providers/managers, those who work in program management/delivery, policy and other primary roles. This included a nurse, administrator, project assistant, consumer, medical scientist (diagnostic), operational support for research, family support worker and therapists (Figure 6).

Respondents worked across different sectors but predominantly the health sector (77 per cent). Other sectors included family/community services (13 per cent), education (7 per cent) and other (3 per cent).

The work of most respondents was based in the state of Victoria (n=66), but all states and territories were represented: Queensland (n=16), Western Australia (n=14), South Australia (n=10), Australian Capital Territory (n=9), New South Wales (n=8), Northern Territory (n=6), Tasmania (n=6) and other countries (n=1).

**Figure 6:** Participant Role (%)




There was a relatively even representation of respondents who worked in the areas of 'Mothers & Babies' (19 per cent), 'Mental Health & Wellbeing' (16 per cent), and 'Development & Learning' (16 per cent) (see Table 1).

**Table 1:** Respondents' work across the defined Focus Areas and other nominated Focus areas

| Focus Areas | Participants, n (n=176) | % |
|---|---|---|
| Mothers & Babies | 19 | 18.8 |
| Mental Health & Wellbeing | 16 | 15.9 |
| Development & Learning | 16 | 15.9 |
| Healthy Environments | 9 | 9.1 |
| Infection, Immunity & Allergy | 9 | 8.5 |
| Organ Health | 7 | 7.4 |
| Obesity & Diabetes | 7 | 6.8 |
| Inequity | 6 | 6.3 |
| **Other Focus Areas** | | |
| Health Services | 5 | 5.1 |
| Work across GenV Focus Areas | 3 | 2.8 |
| Research methods and data | 2 | 1.7 |
| Population screening | 1 | 1.1 |
| Child health research | 1 | 0.6 |

## 4.2 Priorities across the GenV Focus Areas

Table 2 shows the top priority nominated for each of the eight GenV Focus Areas, as well as for the additional five focus areas that participants nominated. It is notable that considering 77 per cent of respondents work in the health sector, the top priorities are broad in nature and have an ecological lens, encompassing healthy environments, services and families. Notably, the top two priorities related to mental health and wellbeing in families, and in mothers and babies.

Priorities related to early childhood development and education, environmental factors impacting on health, prevention of childhood obesity, and access and engagement to services were also identified. Further detail of the top priorities for each focus area and five additional focus areas is provided at Appendix D.

Many of the top six priorities relate to prevention and can be inter-related. For example, early childhood development and education is a critical foundation for children's social and cognitive development. Being unable to access appropriate services for mental health and wellbeing issues can lead to poorer health outcomes. Environmental factors that impact children's health, such as natural disasters or children's sleep, can impact mental health and wellbeing, and the ability to learn. A healthy environment can also include whether the built environment encourages activity levels, play or healthy food options. These in turn can impact early childhood development and childhood obesity.

Further detail of priorities within each focus area is provided at Appendix E.

**Table 2**: Top priorities across Focus Areas

| Rank | Focus Areas | Priorities | Score |
|---|---|---|---|
| 1 | Mothers & Babies | Mothers' & babies' mental health and wellbeing | 63 |
| 2 | Mental Health & Wellbeing | Mental health and wellbeing in families | 40 |
| 3 | Development & Learning | Early childhood development and education | 32 |
| 4 | Healthy Environments | Environmental factors and impacts on health | 30 |
| 5 | Obesity & Diabetes | Prevention of childhood obesity | 22 |
| 6 | Inequity | Access and engagement to services | 18 |
| 7 | Organ Health | Children with medical complexity and chronicity | 13 |
| 8 | Infection, Immunity & Allergy | Medication and epidemiology data | 12 |
| **Other Focus Areas** | | | |
| 9 | Health Services | Paediatric care | 10 |
| 10 | Work across GenV Focus Areas | Development and learning | 7 |
| 11 | Population Screening | Participation and follow up | 6 |
| 12 | Research methods and data | Large sample sizes | 3 |
| 13 | Child health research | Supporting research into child health at MCRI: Equality of opportunity | 3 |

## 4.3 Top priorities across sectors and primary roles

Almost all respondents worked in the health, education and/or family and community services sectors (97 per cent). Survey participants were divided into:

- Three sectors: Health, Education and Family community services sector (Figures 7-9)
- Six primary roles: Researchers, Practitioners, Service providers/managers, Policy, Program management delivery and Other (Figures 10-15).

**Sectors**

Respondents identified as working in one of three sectors: health, education and family community services sector. Figures 7 and 9 shows that the top three priorities listed for those working in the health sector and family community services sector predominantly relate to mental health and wellbeing in families. These were also the highest scoring priorities across the sectors.

**Figure 7:** Health sector focus area priorities

Figures 8 and 9 indicates that many of the priorities listed for those working in the education sector and family community services sector relate to early childhood development and learning (including communication development and access to services) as well as priorities related to healthy environments.

**Figure 8**: Education sector focus area priorities

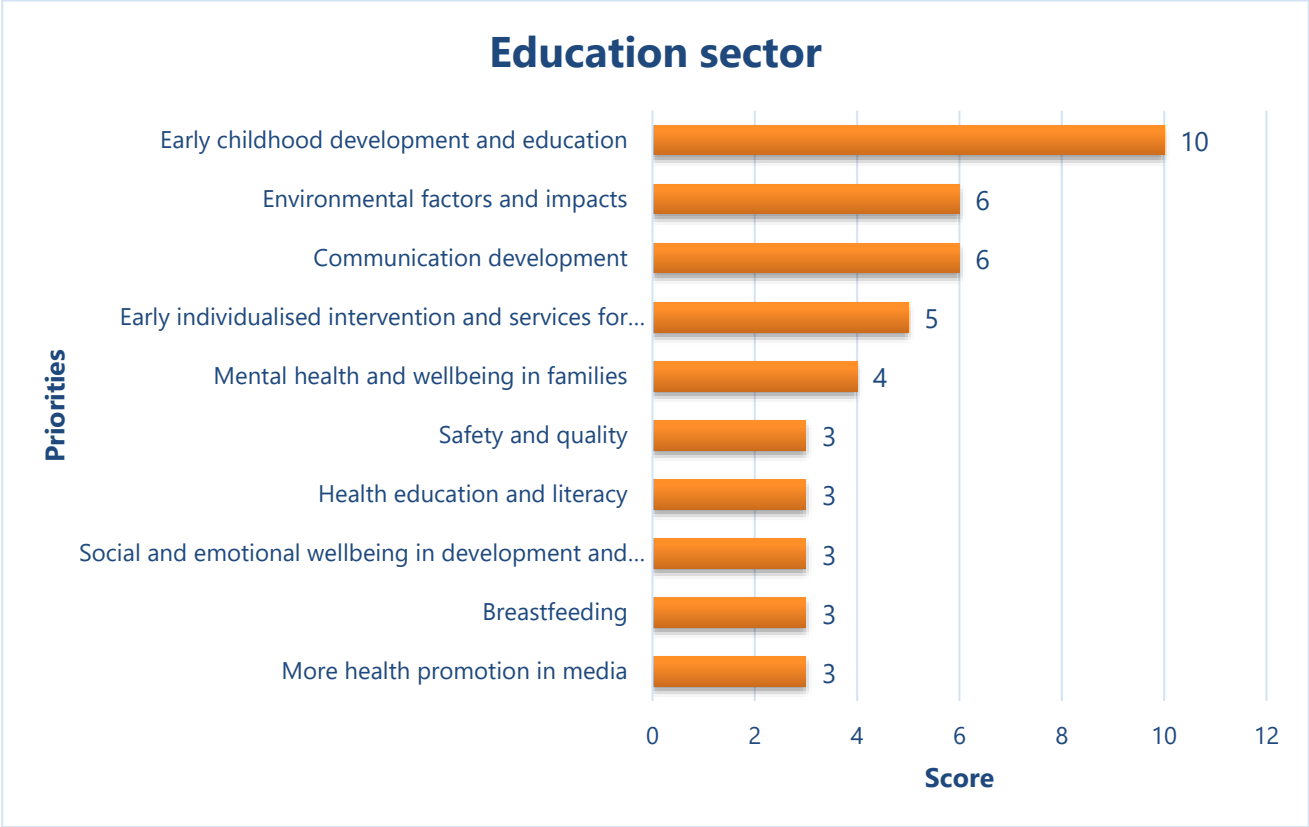



**Figure 9:** Family community services sector focus area priorities

**Primary roles**

Respondents' primary roles included researchers, practitioners, service providers/managers, policy, program managers and other (Figures 10-15).

Overall, the top priorities that featured for practitioners, those working in program management/delivery, policy and other sectors related to mothers' and babies' mental health and wellbeing with scores ranging between 25 and 8. The top priorities that researchers listed were predominantly related to environmental factors and impact (score of 26) while service providers/managers had the highest scoring (12) priorities related to children with medical complexity and chronicity.

**Figure 10:** Researchers focus area priorities

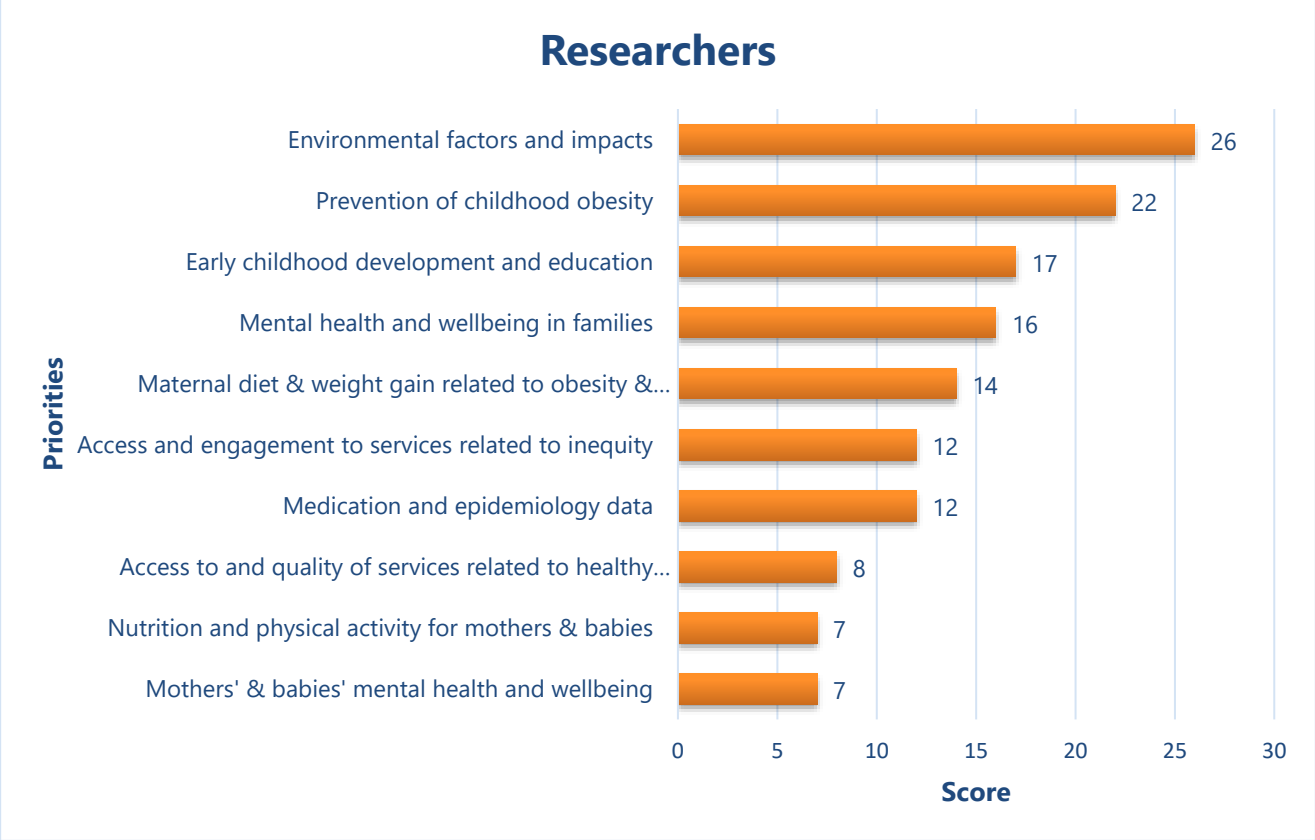


**Figure 11:** Practitioner focus area priorities

**Figure 12:** Service provider/manager focus areas priorities

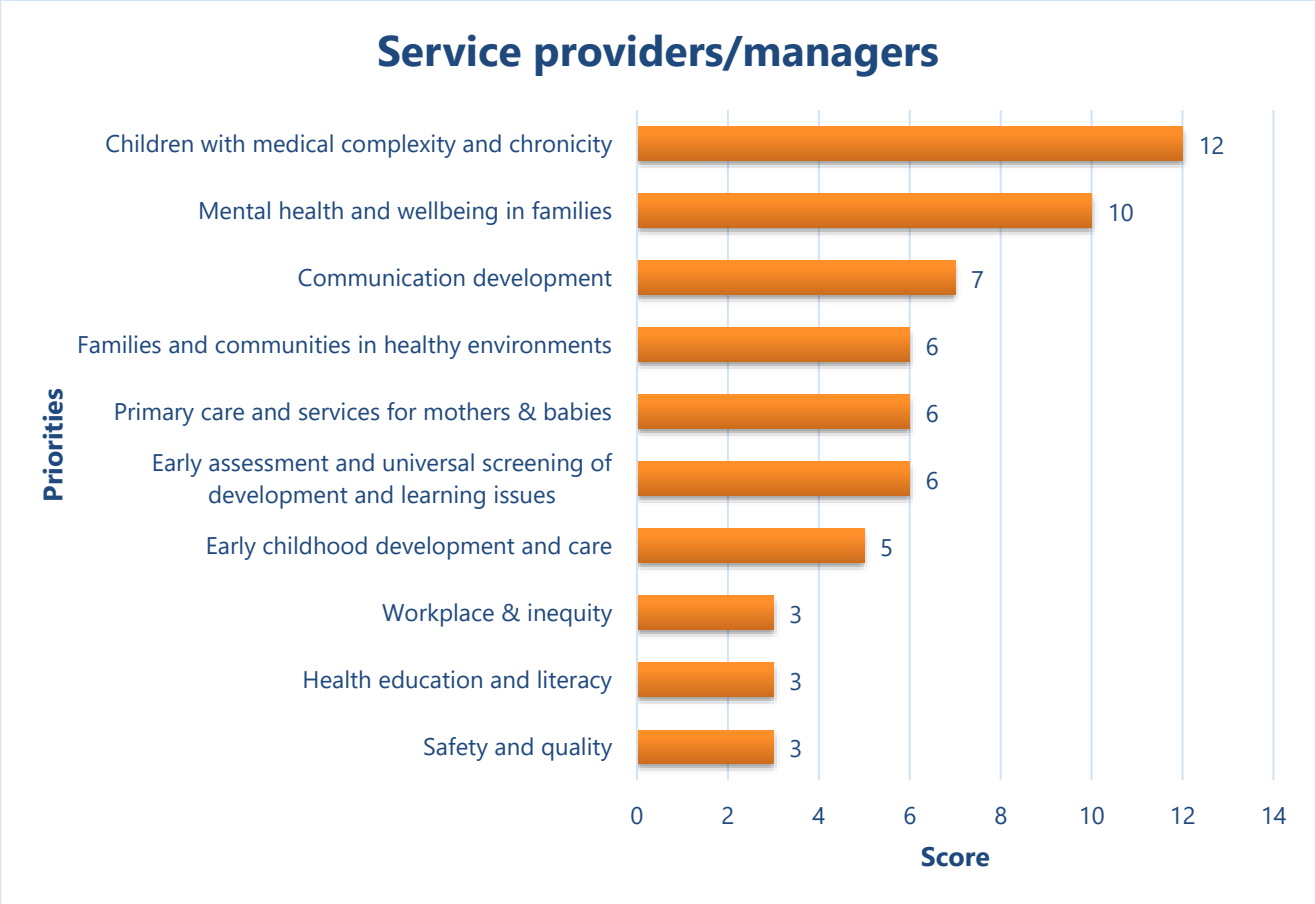


**Figure 13**: Policy focus areas priorities

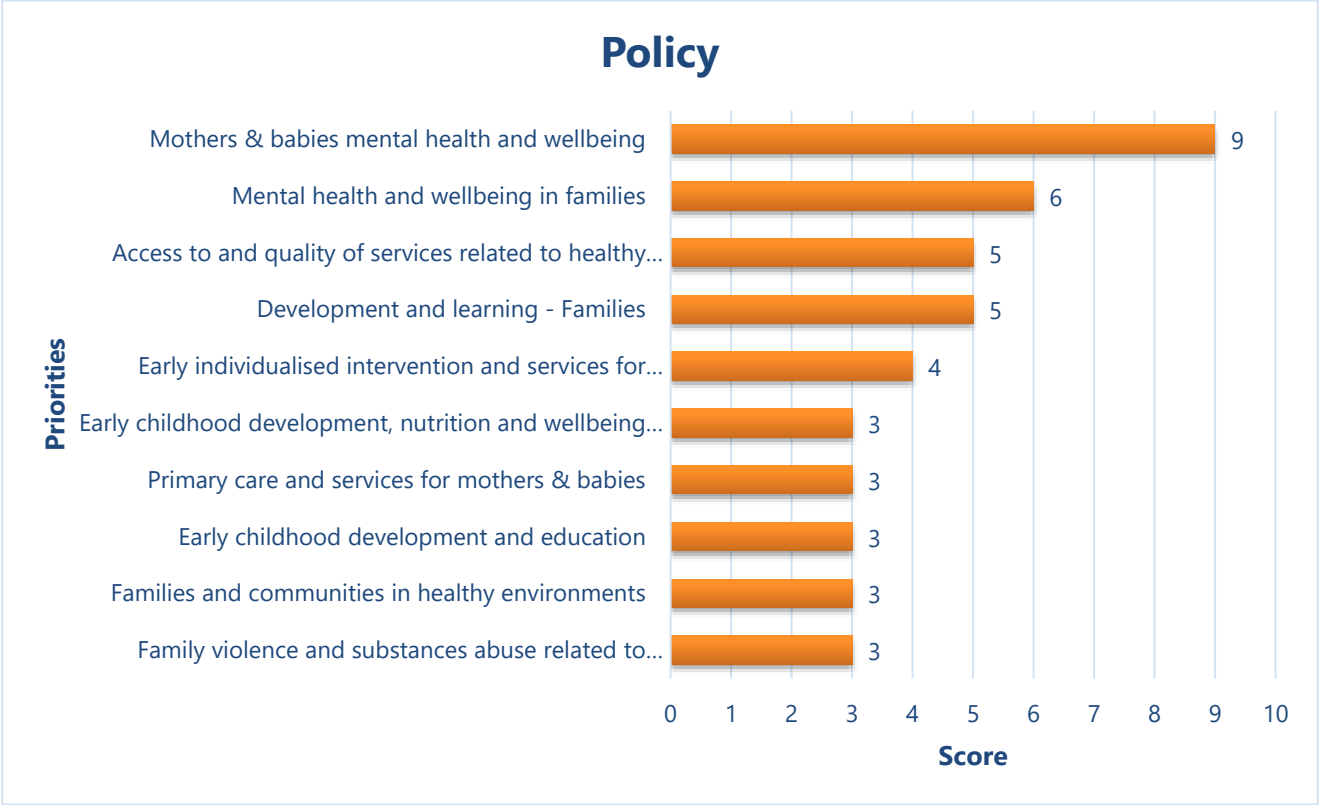
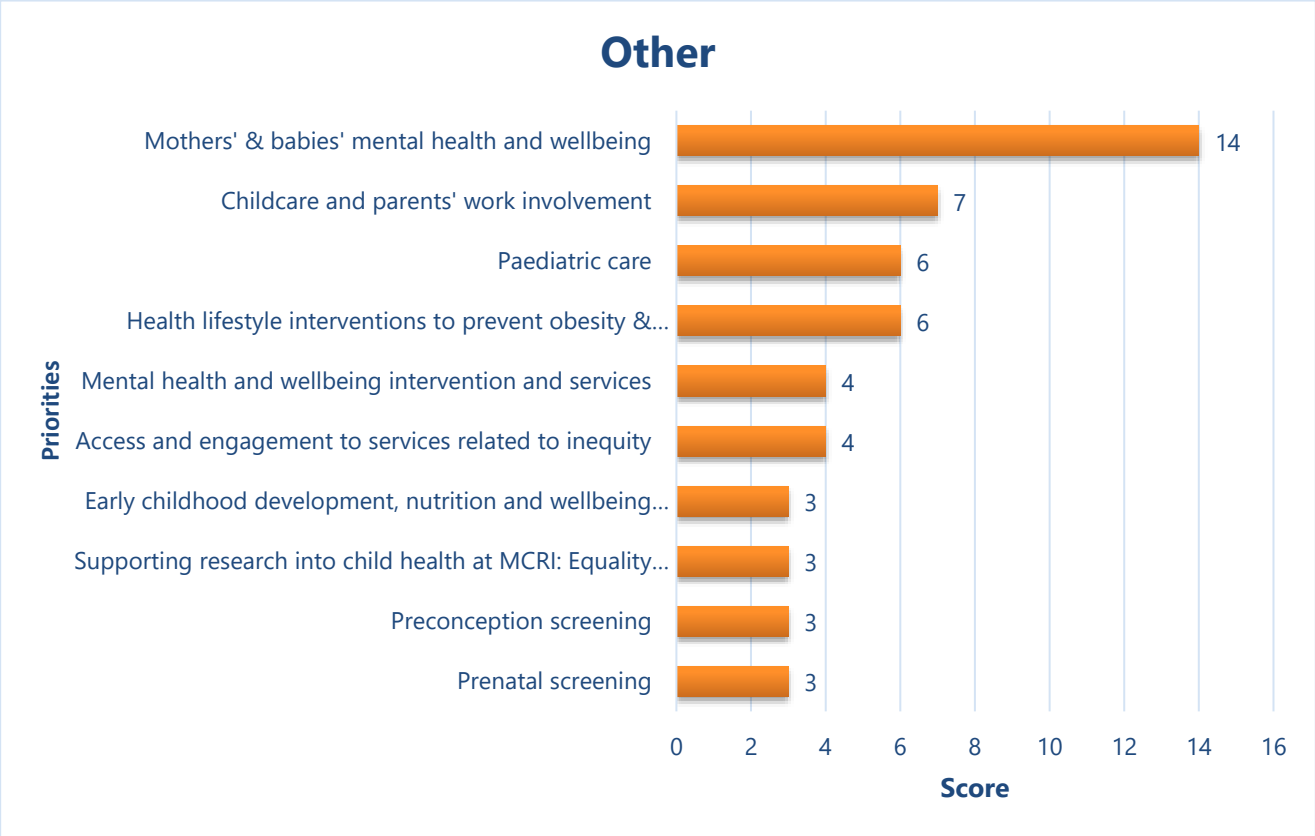



**Figure 14**: Program management focus area priorities

**Figure 15**: Other role focus area priorities




## 4.4 Respondent qualitative comments

Respondents were given the opportunity to comment in their own words on the priority area/s they listed. Comments related to mental health and wellbeing, accessing services, mapping and linking services, data linkage and language development in early childhood (see Appendix F). A selection are outlined below; they highlight the complexity underpinning childhood issues and identify possible solutions.

Respondents made reference to mothers and more generally families experiencing mental health issues and isolation due to a lack of face-to-face social support.

> *Although depression and anxiety are highlighted in research as a major problem for parents, loneliness and isolation perpetuates the problem for parents, and interferes with the first 1000 days brain development in children, which in turn has a lasting impact on their trajectory throughout life. (Mothers & Babies)*

To improve access to social support and parenting skills, respondents made comments on parents accessing services and community support services.

> *Parents won't come to "Parenting Classes" but they will come to supported playgroups that can offer other services/referrals and parenting strategies. These playgroups can be community or school based. (Mental Health & Wellbeing)*

Respondents suggested that particular effort should be made regarding collecting and linking data related to pregnancy, genomics, pathology and other data.

> *Effort should be made to collect as much data as possible on aspects such as pre-pregnancy BMI, pregnancy weight gain, psychological issues in pregnancy. Some of this is linked data, other data will need to specifically ask of parents. (Mental health & wellbeing)*

## 4.5 Datasets

Respondents were asked to think about the top priority area they listed and to list any datasets they knew of that would be relevant to understanding, investigating, evaluation and reporting on the priority. The datasets suggested for the top priorities across the GenV Focus Areas were mostly known by GenV. A list of suggested datasets is provided at Appendix G.

# 5. Discussion

## 5.1 Key findings and considerations for GenV

**Diversity of top five priorities**: This survey asked GenV stakeholders to propose their priorities within the Focus Areas. The most surprising finding of this report was the diversity of the top five priorities chosen. These related to families' mental health and wellbeing (particularly that of mothers and babies), early childhood development and education, environmental factors and impacts on health, as well as prevention of childhood obesity. The top five priorities listed reflect some of the complex issues of our time but they also reflect a socio-ecological approach to childhood including the social determinants of health. The two Lifecourse Frameworks recently published by GenV are guiding our work and specifically include a socio-ecological approach:

- Biodevelopmental framework, which considers the ongoing feedback and interaction between a child's genes, environment, behaviours and, health and learning outcomes.
- Person-centred framework, which outlines the key determinants of Australian children's health and wellbeing.

**Similarity in top priorities across sectors and primary roles**: These top priorities were similar across sectors and primary roles (see Table 3). The complex issues affecting children and parents that feature in the top priorities are well known. A multi-sector approach is likely required to solve these issues. The fact that these issues were identified across sectors supports the necessary breath of GenV and highlights the need for multi-disciplinary and multi-sector approaches for future efforts to help solve these complex issues.

**Table 3**: Summary of top priorities across sectors and primary roles

| Sector/Primary Role | Priorities |
|---|---|
| Health Sector<br>Family Community Services | Mothers' and babies' mental health and wellbeing (scores 36 and 27 respectively) |
| Program management delivery<br>Practitioners<br>Policy<br>Other | Mothers' and babies' mental health and wellbeing (scores ranging from 25 to 8) |
| Researchers | Environmental factors and impact (26) |
| Service providers/managers | Children with medical complexity and chronicity (12) |
| Education | Early childhood development and education (10) |

**Implications for GenV:** The survey's findings have implications for GenV's data collection and engagement across sectors. One of the purposes of conducting this survey was to find out what priorities were important to our users so GenV can ensure we collect data that addresses these priorities. This aligns with GenV's principle that we are inclusive of all data users. This report has identified five broad priorities with mental health being the number one priority. The challenge for GenV will be how to ensure we collect data on these five broad priorities to meet the needs of our users.

Addressing complex issues requires collaboration across systems and sectors focused on a common goal. An important role and principle of GenV is ensuring we have the data to facilitate the necessary collaborations and partnerships across different sectors to positively impact these challenging issues. Only with authentic engagement across wide range of sectors can GenV achieve its vision to help solve complex issues affecting today's children and adults.

These key findings will be used to inform future engagement with researchers, practitioners and policy makers through the GenV website, GenV's working groups and other opportunities. The fact that respondents across sectors identified similar priorities is promising for the future application of GenV.

### 5.2 Strengths and limitations

- **Limitation:** By design, the sample was not representative, so the priorities listed by respondents were not representative of the general population. Respondents worked predominantly in the health sector (77 per cent).
- **Strength:** The survey successfully engaged a relatively large number of diverse respondents working across sectors, states and primary roles (n=176).

## 6. Conclusion

The GenV Focus Area Survey was an important element of GenV's initial engagement with a large number of researchers, practitioners and policymakers across sectors and states. This report finds that families' mental health and wellbeing (particularly that of mothers and babies) was the most important priority identified. The diversity of interests across health and education is well reflected and aligned with GenV's Lifecourse approach.

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# 8. Appendices

## Appendix A: GenV Focus Area Summaries

### Mental Health and Wellbeing

Mental health is a state of emotional and social wellbeing, which influences how an individual copes with the normal stresses of life and whether he or she can achieve his or her potential. From birth, children's mental health is essential for their health, wellbeing and development. Unfortunately, almost 1 in 7 Australian children aged 4-17 years old report a diagnosed mental health problem.

The mental health and wellbeing focus area includes topics such as:

- anxiety and depression
- socio-emotional wellbeing, including resilience and coping
- behavioural problems

It also considers factors that may promote mental health, such as supportive relationships and engagement with community, and factors that contribute to poor mental health such as family violence and social inequities.

### Obesity and Diabetes

Obesity and diabetes result in a range of health complications, including heart and vascular diseases, and are among the leading causes of death and disease for Australian adults (AIHW, 2018). Currently, almost 1 in 4 Australian children and two-thirds of adults are overweight or obese (AIHW, 2017). While the prevalence of diabetes has tripled over the last three decades, with type 1 and type 2 diabetes affecting around 1.2 million Australians aged 18 years and over in 2014–15.

The obesity and diabetes focus area relates to obesity and diabetes in childhood and adulthood. It considers protective and preventative factors such as nutrition and physical activity and risk factors such as unhealthy eating and screen time. It also encompasses government and community initiatives like food labelling and health promotion activities.

### Infection, Immunity and Allergy

Allergy and immune disorders are among the fastest growing chronic diseases in Australia (ASCIA, 2013) with the most recent generation of infants experiencing potentially life-threatening food allergies that were uncommon in previous generations (Tang & Mullins, 2017; McDade, 2012; Milner et al., 2009). Infections are the leading cause of mortality and hospitalization in children. Almost 1 in 5 Australian children are hospitalized at least once before the age of 2 years for an infection (Carville 2007).

The Infection, Immunity and Allergy focus area includes:

- disorders of the immune system such as asthma, autoimmune diseases and food allergies
- interventions, such as the National Immunisation Program
- health and social topics linked to the immune system like gut health, stress and the over-use of antibiotics.

### Development and Learning

Children's early development creates the foundation for lifelong health and wellbeing. Poor childhood

development can have lasting impacts on health, education, and social and economic wellbeing. Differences in developmental outcomes are already apparent by school age. Currently 1 in 5 Australian children are arriving at school developmentally vulnerable (AEDC, 2016) and, cruelly, these vulnerabilities are often borne by already disadvantaged children and families.

The development and learning focus area includes:

- conditions that may influence development and learning such as epilepsy, injury, disability, autism, ADHD, learning difficulties and developmental delay
- programs that support early intervention, prevention and promotion such as early childhood education
- factors that influence development and learning such as education, nutrition, environmental impacts and responsive relationships.

## Organ Health

Children's organs such as their heart, brain, kidney and gut are crucial for healthy development. Disruptions to children's organ health can have a cascade effect on other body systems and organs. The increase in diseases affecting organ health, such as chronic kidney disease, poses a concern for children's quality of life and wellbeing in adulthood.

The Organ Health focus area includes:

- chronic and genetic conditions such as congenital heart disease and chronic kidney disease
- children's physical health and wellbeing, such as heart health, brain health, bone health, gut health and oral health.

## Healthy Environments

A safe, healthy and nurturing environment is key to ensuring all children grow and develop normally and healthily. Children are particularly vulnerable to air pollution, hazardous chemicals, community emergencies (e.g. fires, natural disasters) and inadequate water, sanitation and hygiene. In 2015, reducing environmental risks could have prevented more than a quarter of the 5.9 million deaths of children under 5 years globally (WHO 2017).

The Healthy Environments focus area includes:

- play, sleep and children's environments
- systems, services and community-level factors such as access to green spaces, health/education services and safe housing that enable healthy lifestyles
- barriers to achieving healthy behaviours such as stress, disadvantage, abuse and food and housing insecurity.

## Inequity

Inequity is the presence of systematic and potentially remediable differences among population groups defined socially, economically or geographically. [2]

## Mothers and Babies

Healthy pregnancy and early years ensure the best lifelong outcomes for parents and children.

## Appendix B: Survey invitation

**GenV: Help shape the wellbeing of Australia's children and parents**

**Complete the GenV Survey now**

Our rapidly-changing world is having both positive and negative impacts for today's children and their families. This includes high rates of complex health and development problems, and a search for better ways to promote wellbeing. However, our traditional approaches to problem-solving and research are struggling to keep pace at the rate we need.

Generation Victorian (GenV) is an initiative led by the Murdoch Children's Research Institute and backed by the Victorian Government. It will help address these issues by better linking existing data, supplemented with data from up to 170,000 Victorian children born between 2021-2022 and their parents, telling a holistic story of lifelong health and wellbeing.

Policy-makers, researchers, service providers, educators and practitioners will be able to use GenV's powerful data to accelerate the discovery of solutions for children and parents today.

We need your contribution to ensure that GenV knows about the questions confronting you.

**Please help us to understand your needs by completing** GenV's Focus Area Survey. The survey will remain open until **9:00am Monday 23 September 2019**. **Your input is important and can help to shape GenV's priorities, data and resources.**

**For more information, please contact the GenV team at** solutionsgenv@mcri.edu.au

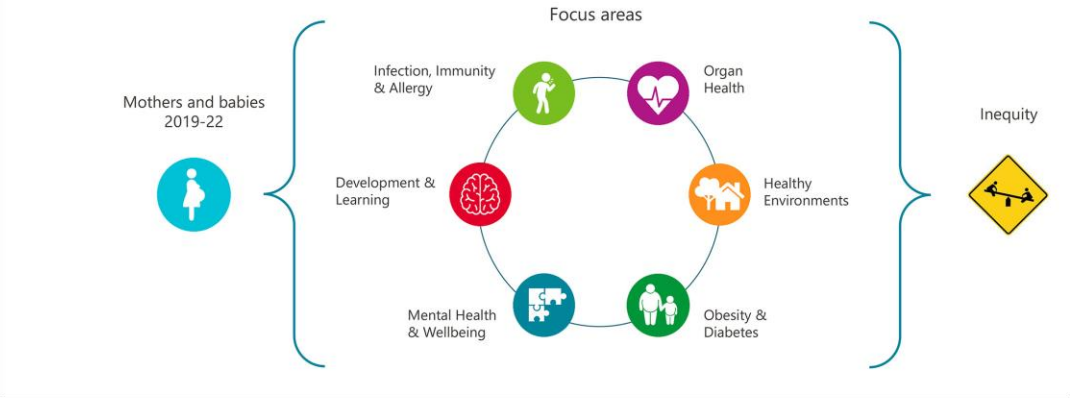
# Appendix C: Focus Area REDCap Survey

*Confidential*



## GenV Focus Area Survey

Thank you for participating in GenV's Focus Area Survey
GenV supports collaborations to improve wellbeing and address pressing problems experienced by children and parents. GenV has developed a Focus Area Framework comprising six defined areas that frequently impact on children, parents, families and the community. This framework considers 'Inequity' across all focus areas and is initially concentrating on the first thousand days; the 'Mothers & Babies' life stage.




1. Mental Health & Wellbeing
Social and emotional wellbeing throughout life to support resilience and mental health
2. Development & Learning
Pathways that can build the foundation for lifelong development and learning
3. Infection, Immunity & Allergy
Lower risk of allergy and immune disorders through effective prevention strategies and clinical care
4. Obesity & Diabetes
Behaviours and mechanisms that provide a foundation for future health
5. Organ Health
All body systems on their healthiest trajectory and free of disease, eg cardiovascular, gut, bone, lung, hearing, vision and oral health
6. Healthy Environments
Healthy family, built and social environments
7. Mothers & Babies
Healthy pregnancy and early years ensure the best lifelong outcomes for parents and children
8. Inequity
Children having the same opportunities from birth for health, education, inclusion and participation

Thinking about the first 1000 days of a life (from conception to roughly age 2 years) for children and their parents, we are seeking your feedback on:
a) the focus areas, and their specific priorities most relevant to your work,
b) the kinds of datasets relevant to your priorities.

Your input is important and can help to shape GenV's priorities, data and resources.

The Focus Area survey will take approx. 10 minutes to complete. We'll share the results on GenV's website and newsletter. We may also write up the anonymous summary results into a report.

# Appendix D: Top priorities for each focus area

Table D1.1 outlines the top priorities for each focus area

**Table D1.1**: Priorities for each Focus Area

| Rank | Priority | Score |
|---|---|---|
| **Mental Health & Wellbeing** | | |
| 1 | Mental health and wellbeing in families | 40 |
| 2 | Mental health and wellbeing intervention and services | 16 |
| 3 | Child protection | 13 |
| 4 | Mental health and social support | 10 |
| 5 | Early childhood development and care | 9 |
| **Development & Learning** | | |
| 1 | Early childhood development and education | 32 |
| 2 | Communication development | 18 |
| 3 | Development and learning - Families | 17 |
| 4 | Early individualised intervention and services for development and learning issues | 15 |
| 5 | Early assessment and universal screening of development and learning issues | 6 |
| 5 | Neurodisability and rehabilitation | 6 |
| **Infection, Immunity & Allergy** | | |
| 1 | Medication and epidemiology data | 12 |
| 2 | Infections | 10 |
| 3 | Vaccinations | 7 |
| 4 | Antibiotics | 6 |
| 5 | Prevention of allergic illnesses | 5 |
| **Obesity & Diabetes** | | |
| 1 | Prevention of childhood obesity | 22 |
| 2 | Maternal diet & weight gain related to obesity & diabetes | 15 |
| 3 | Health lifestyle interventions to prevent obesity & diabetes | 7 |
| 4 | Healthy food choices | 6 |
| 5 | Infant feeding/Breastfeeding related to obesity & diabetes | 5 |
| **Organ Health** | | |
| 1 | Children with medical complexity and chronicity | 13 |
| 2 | Familial Hypercholesterolaemia | 6 |
| 2 | Oral health | 6 |
| 2 | Thrombosis and Haemostasis | 6 |
| 2 | Vision development | 6 |
| 3 | Hearing screening | 3 |
| 3 | Hypertension | 3 |
| 3 | Long-term outcome of congenital anomalies | 3 |
| 4 | Urological diseases | 2 |
| **Healthy Environments** | | |
| 1 | Environmental factors and impacts on health | 30 |
| 2 | Families and communities in healthy environments | 17 |
| 3 | Access to and quality of services | 14 |
| 4 | Inequitable environments perpetuating health inequities | 3 |

| Rank | Priority | Score |
|---|---|---|
| 4 | More health promotion in media | 3 |
| 4 | Food security and knowledge transfer | 3 |
| **Mothers & Babies** | | |
| 1 | Mothers' & babies' mental health and wellbeing | 63 |
| 2 | Primary care and services for mothers & babies | 16 |
| 3 | Nutrition and physical activity for mothers & babies | 15 |
| 4 | Breastfeeding | 12 |
| 5 | Pregnancy and birth complications | 11 |
| **Inequity** | | |
| 1 | Access and engagement to services related to inequity | 18 |
| 2 | Migrant health | 6 |
| 3 | Policy and Government related to inequity | 5 |
| 4 | Support for families experiencing social adversity | 5 |
| 5 | Parent education, support & resources related to inequity | 4 |
| **Other Focus Areas** | | |
| **Health Services** | | |
| 1 | Paediatric care | 10 |
| 2 | Safety and quality | 9 |
| 3 | Procedural pain management | 7 |
| 4 | Aboriginal Health | 6 |
| 5 | Health education and literacy | 4 |
| **Research methods and data** | | |
| 1 | Large sample sizes | 3 |
| 2 | Registry Randomised Trials - Immunisation compliance | 3 |
| 3 | Quality research questions | 3 |
| **Child health research** | | |
| 1 | Supporting research into child health at MCRI: Equality of opportunity | 3 |
| 2 | Supporting research into child health at MCRI Impact of parenting on health | 2 |
| 3 | Supporting research into child health at MCRI: Exercise & nutrition | 1 |
| **Population screening** | | |
| 1 | Participation and follow up | 6 |
| 2 | Preconception screening | 3 |
| 3 | Prenatal screening | 3 |
| **Work across GenV Focus Areas** | | |
| 1 | Development and learning | 7 |
| 2 | Inequity | 5 |
| 2 | Mental Health | 5 |
| 2 | Mothers & Babies | 5 |
| 3 | Infection, Immunity & Allergy | 4 |
| 4 | Healthy Environments | 2 |
| 5 | Obesity & Diabetes | 2 |

## Appendix E: Frequencies of focus area priorities

Table E1.1 outlines the priorities that respondents listed across the three priority areas.

**Table E1.1:** Frequencies of Focus Area Priorities

| **Mental health & Wellbeing (n=28)** | **Priority 1 (n=16)** | **%** | **Priority 2 (n=16)** | **%** | **Priority 3 (n=15)** | **%** |
|---|---|---|---|---|---|---|
| | Mental health and wellbeing in families | 50 | Mental health and wellbeing in families | 31 | Mental health and wellbeing in families | 40 |
| | Child protection | 13 | Mental health and wellbeing intervention and services | 25 | Child protection | 20 |
| | Mental health and wellbeing intervention and services | 13 | Early childhood development and care | 19 | Mental health and social support | 20 |
| | Mental health and social support | 6 | Child protection | 13 | Mental health and wellbeing intervention and services | 13 |
| | Prevention strategies related to mental health and wellbeing | 6 | Mental health and social support | 13 | Early identification/diagnosis of mental health and wellbeing issues | 7 |
| | Early childhood development and care | 6 | | | | |
| | Early identification/diagnosis of mental health and wellbeing issues | 6 | | | | |

| **Development and learning (n=28)** | **Priority 1 (n=18)** | **%** | **Priority 2 (n=16)** | **%** | **Priority 3 (n=16)** | **%** |
|---|---|---|---|---|---|---|
| | Early childhood development and education | 22 | Early childhood development and education | 56 | Early individualised intervention and services for development and learning issues | 38 |
| | Development and learning - Families | 17 | Development and learning - Families | 19 | Communication development | 31 |
| | Early individualised intervention and services for development and learning issues | 17 | Communication development | 13 | Development and learning - Families | 13 |
| | Communication development | 17 | Social and emotional wellbeing in development and learning | 6 | Early childhood development and education | 13 |
| | Early assessment and universal screening of development and learning issues | 11 | Neurodisability and rehabilitation | 6 | Neurodisability and rehabilitation | 6 |
| | Children's daily activities | 6 | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| | Social and emotional wellbeing in development and learning | 6 | | | | |
| | Neurodisability and rehabilitation | 6 | | | | |

| **Infection, Immunity & Allergy (n=15)** | **Priority 1 (n=8)** | **%** | **Priority 2 (n=8)** | **%** | **Priority 3 (n=6)** | **%** |
|---|---|---|---|---|---|---|
| | Infections | 25 | Vaccinations | 25 | Infections | 33 |
| | Medication and epidemiology data | 25 | Medication and epidemiology data | 25 | Medication and epidemiology data | 33 |
| | Antibiotics | 13 | Antibiotics | 13 | Antibiotics | 17 |
| | Vaccinations | 13 | Infections | 13 | Hospital/GP visits | 17 |
| | Prevention of allergic illnesses | 13 | Prevention of allergic illnesses | 13 | | |
| | Improving engagement and health literacy | 13 | Hospital/GP visits | 13 | | |

| **Obesity & Diabetes (n=12)** | **Priority 1 (n=10)** | **%** | **Priority 2 (n=11)** | **%** | **Priority 3 (n=10)** | **%** |
|---|---|---|---|---|---|---|
| | Prevention of childhood obesity | 50 | Prevention of childhood obesity | 18 | Prevention of childhood obesity | 30 |
| | Maternal diet & weight gain related to obesity & diabetes | 30 | Maternal diet & weight gain related to obesity & diabetes | 18 | Maternal diet & weight gain related to obesity & diabetes | 20 |
| | Healthy food choices | 10 | Infant feeding/Breastfeeding related to obesity & diabetes | 18 | Health lifestyle interventions to prevent obesity & diabetes | 20 |
| | Health lifestyle interventions to prevent obesity & diabetes | 10 | Healthy food choices | 9 | Healthy food choices | 10 |
| | | | Poverty related to obesity & diabetes | 9 | Infant feeding/Breastfeeding related to obesity & diabetes | 10 |
| | | | Access to services related to obesity & diabetes | 9 | Weight gain | 10 |
| | | | Drivers/mechanisms of health behaviour | 9 | | |
| | | | Health lifestyle interventions to prevent obesity & diabetes | 9 | | |

| Organ Health (n=13) | Priority 1 (n=10) | % | Priority 2 (n=7) | % | Priority 3 (n=7) | % |
|---|---|---|---|---|---|---|
| | Children with medical complexity and chronicity | 20 | Children with medical complexity and chronicity | 29 | Children with medical complexity and chronicity | 43 |
| | Long-term outcome of congenital anomalies | 10 | Oral health | 14 | Oral health | 14 |
| | Oral health | 10 | Vision development | 14 | Vision development | 14 |
| | Vision development | 10 | Urological diseases | 14 | Familial Hypercholesterolaemia | 14 |
| | Hearing screening | 10 | Familial Hypercholesterolaemia | 14 | Thrombosis and Haemostasis | 14 |
| | Hypertension | 10 | Thrombosis and Haemostasis | 14 | | |
| | Familial Hypercholesterolaemia | 10 | | | | |
| | Thrombosis and Haemostasis | 10 | | | | |
| | Unsure | 10 | | | | |

| Healthy Environments (n=16) | Priority 1 (n=13) | % | Priority 2 (n=12) | % | Priority 3 (n=12) | % |
|---|---|---|---|---|---|---|
| | Environmental factors and impacts | 46 | Families and communities in healthy environments | 33 | Environmental factors and impacts | 33 |
| | Access to and quality of services related to healthy environments | 23 | Environmental factors and impacts | 33 | Families and communities in healthy environments | 25 |
| | Families and communities in healthy environments | 15 | Access to and quality of services related to healthy environments | 17 | Access to and quality of services related to healthy environments | 8 |
| | Inequitable environments perpetuating health inequities | 8 | Lack of longitudinal data | 8 | Gene environment interactions | 8 |
| | More health promotion in media | 8 | Food security and knowledge transfer | 8 | Unclear pathways and mechanisms | 8 |
| | | | | | Food security and knowledge transfer | 8 |
| | | | | | Physical exercise | 8 |

| Mothers & Babies (n=33) | Priority 1 (n=24) | % | Priority 2 (n=24) | % | Priority 3 (n=24) | % |
|---|---|---|---|---|---|---|
| | Mothers' & babies' mental health and wellbeing | 50 | Mothers' & babies' mental health and wellbeing | 46 | Mothers' & babies' mental health and wellbeing | 21 |
| | Breastfeeding | 17 | Primary care and services for mothers & babies | 17 | Primary care and services for mothers & babies | 21 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | Nutrition and physical activity for mothers & babies | 13 | Early childhood development, nutrition and wellbeing (mothers & babies) | 13 | Early childhood development, nutrition and wellbeing (mothers & babies) | 17 |
| | Pregnancy and birth complications | 8 | Childcare and parents' work involvement | 8 | Nutrition and physical activity for mothers & babies | 17 |
| | Primary care and services for mothers & babies | 4 | Nutrition and physical activity for mothers & babies | 4 | Childcare and parents' work involvement | 13 |
| | Family violence and substances abuse related to mothers & babies | 4 | Pregnancy and birth complications | 4 | Pregnancy and birth complications | 13 |
| | Mothers & babies at risk populations | 4 | Mothers & babies at risk populations | 4 | | |
| | | | Mothers' & babies' chronic disease | 4 | | |

| **Inequity (n=11)** | **Priority 1 (n=8)** | **%** | **Priority 2 (n=7)** | **%** | **Priority 3 (n=7)** | **%** |
|---|---|---|---|---|---|---|
| | Access and engagement to services related to inequity | 50 | Access and engagement to services related to inequity | 29 | Access and engagement to services related to inequity | 29 |
| | Policy and Government related to inequity | 13 | Parent education, support & resources related to inequity | 29 | Support for families experiencing social adversity | 29 |
| | Support for families experiencing social adversity | 13 | Preventing vulnerability by early intervention | 14 | Migrant health | 14 |
| | Migrant health | 13 | Policy and Government related to inequity | 14 | Health and nutrition related to inequity | 14 |
| | Workplace & inequity | 13 | Migrant health | 14 | ADHD related to inequity | 14 |

| **Health services (n=9)** | **Priority 1 (n=6)** | **%** | **Priority 2 (n=6)** | **%** | **Priority 3 (n=6)** | **%** |
|---|---|---|---|---|---|---|
| | Aboriginal Health | 33 | Paediatric care | 50 | Procedural pain management | 33 |
| | Safety and quality | 33 | Procedural pain management | 17 | Health education and literacy | 33 |
| | Procedural pain management | 17 | Safety and quality | 17 | Paediatric care | 17 |
| | Paediatric care | 17 | Health education and literacy | 17 | Safety and quality | 17 |

| Research methods and data (n=3) | Priority 1 (n=2) | % | Priority 2 (n=1) | % | Priority 3 (n=1) | % |
|---|---|---|---|---|---|---|
| | Large sample sizes | 50 | Quality research questions | 100 | Quality research questions | 100 |
| | Registry Randomised Trials - Immunisation compliance | 50 | | | | |

| Child health research (n=1) | Priority 1 (n=1) | % | Priority 2 (n=1) | % | Priority 3 (n=1) | % |
|---|---|---|---|---|---|---|
| | Supporting research into child health at MCRI: Equality of opportunity | 100 | Supporting research into child health at MCRI Impact of parenting on health | 100 | Supporting research into child health at MCRI: Exercise & nutrition | 100 |

| Population screening (n=2) | Priority 1 (n=2) | % | Priority 2 (n=2) | % | Priority 3 (n=2) | % |
|---|---|---|---|---|---|---|
| | Participation and follow up | 50 | Participation and follow up | 50 | Participation and follow up | 50 |
| | Preconception screening | 50 | Prenatal screening | 50 | Prenatal screening | 50 |

| Work across GenV Focus Areas (n=5) | Priority 1 (n=5) | % | Priority 2 (n=5) | % | Priority 3 (n=5) | % |
|---|---|---|---|---|---|---|
| | Mothers & Babies | 20 | Development and learning | 40 | Healthy Environments | 40 |
| | Development and learning | 20 | Mothers & Babies | 20 | Mental Health | 40 |
| | Inequity | 20 | Inequity | 20 | Infection, Immunity & Allergy | 20 |
| | Infection, Immunity & Allergy | 20 | Obesity & Diabetes | 20 | | |
| | Mental Health | 20 | | | | |

## Appendix F: Survey respondent comments

**Focus Area Survey: Qualitative Responses**

At the conclusion of the survey, respondents were able to provide additional comments on the focus area(s) and priorities they had selected and listed. The key themes that arose related to mental health issues and social support, access to and provision of services,

**Mental health & wellbeing in families**

Three respondents made reference to mothers and more generally families experiencing mental health issues and isolation due to a lack of face-to-face social support:

> *Anxiety is one of the key issues for new mothers and affects ability to attach (Mothers & Babies)*
>
> *Although depression and anxiety are highlighted in research as a major problem for parents, loneliness and isolation perpetuates the problem for parents, and interferes with the first 1000 days brain development in children, which in turn has a lasting impact on their trajectory throughout life. (Mothers & Babies)*
>
> *Mothers are becoming increasingly isolated and reliant on digital media for social interaction and sources of information. This gives them a skewed view of the world and their role as parents. I would like to see a return to face to face interactions and real life friendships. (Mental health & wellbeing)*

**Families accessing support and community services**

To improve access to social support and parenting skills, respondents made comments on parents accessing services and community support services including early childhood centres:

> *We run a Peep program, which stands for Parents Early Education Partnership. It is a facilitated playgroup, where we support and encourage parents to be their child's first, most important and ongoing teacher. (Mental Health & Wellbeing)*
>
> *Parents won't come to "Parenting Classes" but they will come to supported playgroups that can offer other services/referrals and parenting strategies. These playgroups can be community or school based. (Mental Health & Wellbeing)*
>
> *A high quality early childhood centre that is accessible and affordable has been shown to improve children's life chances. It can also be a great support to families. [...] Teachers have been shown by research to be the key factor to achieving high quality, and high quality the key factor to later life success for children. (Obesity & Diabetes)*

While parent support and parenting skills were highlighted as key areas to consider, respondents also commented on primary health, health literacy education and housing services being available to families in socioeconomic disadvantaged areas.

> *There are many facets to the issues facing families within the first 1000 days, and ensuring stable families with good parenting skills is essential, but they will never be able to focus on these unless basic needs of housing and food are met first. (Mental health & wellbeing)*
>
> *Additional primary health services and supports (including Allied Health) should be provided in areas of known socioeconomic disadvantage. (Infection, Immunity & Allergy)*
>
> *I work with the families who are poor and vulnerable. Many of the parents that I work with have low levels of education and poor literacy and numeracy skills. They have had poor role models in*


DOI:10.25374/MCRI.13003985

*regards to their parenting experience and many have limited social and emotional supports. Often these clients need emotional and material resources to care for their families and the opportunity to improve their life skills through access to education at a range of levels that give them access to a range of opportunities. (Inequity)*

One respondent made a suggestion that parents need to attend child health clinics regularly to help identify any risk factors.

> *[Families] need to attend child health nurse clinic regularly. Have more time for identifying any issues than busy GPs. Should have to have regular checks linked to family payments, not just immunisation status to enable early recognition of issues and intervention. (Development & Learning)*

**Barrier to accessing support services**

Respondents also warned of barriers experienced by at-risk families in seeking and engaging with support and services and suggested approaches to overcoming these barriers.

> *Barriers to seeking and engaging supports need to be identified and addressed in business rules and strategic plans (i.e. roles that undertake care co-ordination, booking and scheduling practices, referral and follow up pathways), specific for families experiencing vulnerability (either transient or long term vulnerabilities). (Inequity)*

> *Many at-risk mums-to-be are not presenting early nor regularly at birthing hospitals. [...] The cogs for social intervention from the birthing hospital grind too slowly to afford any support to the family, with a plethora of support in the community sector, the options are bewildering. Often the risk adverse reaction of the birthing hospital is to remove the infant. Turning the hospital system around from them seeing child removal as the 'safest option', to being seen as welcoming and supportive to at- risk mother-to-be, rather than those families being afraid of presenting at hospital for fear of judgement and child removal, will be a slow process. There needs to be greater coordination of community support, less risk aversion from community services, more opportunity for community services to work in real partnership with Child Protection (CP) with clear bottom lines from CP and a coordinated response from that myriad of support services out there. That means that one NGO agency is the lead agency - coordinating all the services around the family - not just referring families to all the support required - DOA, Housing, Police, Health etc but keeping the services accountable and tracking the progress of the at risk family. (Mental Health & Wellbeing)*

**Children receiving diagnoses and access to health services**

One respondent with an interest Mental Health and Wellbeing highlighted that infants '*need rapidly responsive diagnostic and intervention services [...] with developing behavioural and developmental problems"*. While, another respondent made the suggestion that:

> *Children with chronic health conditions require child centred and developmentally appropriate / individualised preparation and support for medical procedures to avoid trauma. (Mental health & wellbeing)*

Another highlighted the importance of funding home-based care for children under the age of year 2 with medical complexities and chronicity to aid the reducing the burden on families.

> *Families with children with medical complexity and chronicity are providing excellent often complex medicalised care at home for their children - this, in decreasing the burden on the health system increases the burden on families. Families are dealing with not only chronic grief and*


DOI:10.25374/MCRI.13003985

*sorrow but also carer fatigue and exhaustion, this impacts the carers' health and mental health which they often do not take time to address. In home care and support for families with children under the age of 2 with complex health care needs is not always supported by NDIS funding. This is particularly true if these children live in rural and remote settings. Issues to be addressed and prioritised. (Development & learning)*

**Mapping and linking services**

A number of respondents referred to the importance of mapping and linking health and community services so that 'silos' could be prevented between different services that families often access.

*[There should be] better handover from antenatal care providers, GPs to other services and vice versa. Eg. History mental health issues, family supports, stressors all attended by all AN professional. (Development and learning)*

*Agreements/MOUs between services for information sharing under state based legislation. Mapping of support services would diminish the 'silos' between acute and primary health care and NGOs/support services. Primary Health Networks have attempted to map through health pathways, but this is only from a health perspective. The whole of community response (i.e. health and human services) would need to include supports that address the social determinants of health that impact on the first 1000 days. A lack of knowledge in general means that optimal provision of services does not occur. (Development & learning)*

**Data quality and linkage**

Three respondents indicated that there were gaps in data related to preconception, post-partum, medications and the environment which contributes to the challenge of measuring health impacts and outcomes.

*[There are] many data sets but weight is poorly recorded preconception and post-partum (Healthy Environments)*

*Distinct lack of preconception data. No universal coverage. No national policy. (Mothers & Babies)*

*There are also gaps in the data related to medications (i.e. prescriptions for public inpatients, private scripts, emergency department, remote aboriginal health services) (Organ Health)*

*Unfortunately data relating to pollution is not provided at a very granular level. This makes it difficult to measure the health impacts on our daily lives. (Healthy Environments)*

Two respondents suggested that particular effort should be made with regards to collecting and linking data related to pregnancy, genomics, pathology and other data.

*Effort should be made to collect as much data as possible on aspects such as pre-pregnancy BMI, pregnancy weight gain, psychological issues in pregnancy. Some of this is linked data, other data will need to specifically ask of parents. (Mental health & wellbeing)*

*Data linkage between the identified data collections (and others) is needed to really deliver value. Genomics, pathology and other data also of value (Organ health)*

**Scoping and linking datasets**

One respondent with an interest in Organ Health highlighted, "*There is a lack of understanding around what data items are collected, if they're accessible*". To overcome this challenge, two respondents provided in-depth comments on the importance of scoping and identifying opportunities for data linkage with GenV across an array of different services.


DOI:10.25374/MCRI.13003985

*We need extensive review and consultation to scope all the relevant datasets, for example with DHHS regarding Family Services datasets that would be applicable for inclusion, e.g. Child Protection, and the accessibility of these given confidentiality considerations. Similarly full review and consultation with CCOPMM regarding the health and social datasets used in their reviews to date and how these should intersect with GenV. To fully realise health care provision and 'health care gaps' we would need good coverage of as many health care providers as possible including public and private providers, particularly for services where a substantial proportion of child health care provision is provided privately e.g. dental, speech and language, mental health ... Fully understanding this area requires a breadth of services including social provision such as housing, parental health care support (e.g. addiction services), child health and educational services... To be comprehensive these data would need to be extensive and consider health and care outside of the mainstream 'health service', e.g. health and mental health care provided within the justice system, and frontline acute mental health incidents supported by emergency services including the police. This needs to be fully scoped with regard to which datasets should be core to GenV from the outset and capacity for future linkage. (Development & learning)*

**Communication development**

Finally, respondents also made reference to early childhood development especially with regards to technology impacting language development.

*Technology has impacted the time and way families communicate. Children, in first 2000 days, need language to be modelled and need to be encouraged in their attempts to make sounds, babble and talk, feedback from adults in the home provides this. Technology in some cases draws adult attention away from interactions with infants and children. (Mental health & wellbeing)*

*Children are increasingly delayed in speech, which is a direct result of lack of meaningful and sufficient interaction with caregivers. Children are spending too much time in front of screens, as are parents, and this is impacting on the quality of interactions with each other. (Development & Learning)*

*Many cultures don't have the same emphasis on reading and singing songs and nursery rhymes to children from womb to 2 years old. Children come to school 3 years behind with their oral language skills. Teaching parents the importance of reading & singing even to unborn and infants is vital for later life. (Development & learning)*


DOI:10.25374/MCRI.13003985

## Appendix G: Datasets

Datasets listed by respondents are outlined in the Table G1.1. Note that some of those suggested are only available for research samples, while others are potential sources rather than datasets.

**Table G1.1:** Datasets listed by respondents

| Focus Area & Top Priority | Datasets |
|---|---|
| **Mothers & Babies:** Mothers & babies mental health and wellbeing | |
| | National Nutrition Survey |
| | Victoria Population Health survey |
| | Australian Bureau of Statistics |
| | Medicare and data on services used |
| **Mental health & Wellbeing:** Mental health and wellbeing in families | |
| | Maternal Child Health Record |
| | Hospital Electronic Medical Record |
| | Maternity |
| | Mental health services data |
| | Primary care data |
| | Longitudinal Study of Australian Children (LSAC) |
| | Australian Bureau of Statistics |
| | data.gov.au |
| | Mapping Economic Disadvantage (maps.ncoss.org.au) |
| | Right @home nurse home visiting program evaluation |
| **Healthy environments:** Environmental factors and impacts on health | |
| | iWHP held by WHO |
| | Australian Institute of Health and Welfare pregnancy data set |
| | Australian Longitudinal Study on Women's Health |
| | Raine study |
| | Lucina |
| **Obesity & diabetes:** Prevention of childhood obesity | |
| | Australian Early Development Census |
| | AIHW |
| | Australian indigenous healthinfonet |
| | Consumer feedback |
| | Health reports |


DOI:10.25374/MCRI.13003985