Accelerating solutions for healthier Victorian children

murdoch children's research institute

Developing GenV's Research Methodologies: Brainstorming Sessions and Survey 2018

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Abstract

To inform GenV's early development, the Solutions Hub assembled seven rapid Research Methodology Brainstorming Sessions through March-May 2018 followed by a survey to prioritise the unique ideas generated. Many of the prioritised ideas have since been taken forward by GenV Method Core and Focus Area Working Groups ahead of the Cohort 2020s recruitment in 2021-22. Others have emerged, reflecting broader input since the initial sessions. Overall, this activity kick-started significant value to the research and translational impacts of GenV.

Keywords

Research methodology, Brainstorming sessions, Survey

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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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List of Abbreviations & Glossary

BMI	Body mass index
BP	Blood pressure
CSIRO	Commonwealth Scientific and Industrial Research Organisation
CMV	Cytomegalovirus
CVS	Chorionic villous sample
EMR	Electronic medical record
GenV	Generation Victoria, an initiative led from the MCRI - aims to improve the futures of Victoria's children establishing one of the world's largest birth cohorts
GIS	Geographic Information System
GTT	Glucose tolerance test
HRQL	Health-related quality of life
LGA	Local government area
GWAS	Genome-wide association study (genotyping)
GBS	Prenatal Group B Streptococcal swab at 36 weeks pregnancy
MCC	Melbourne Children's Campus: MCRI, The Royal Children's Hospital and The University of Melbourne
MCRI	Murdoch Children's Research Institute
SES	Socioeconomic status
VCGS	Victorian Clinical Genetics Services
VSN	Victorian Student Number

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1. Executive Summary

Generation Victoria's vision is to help solve complex issues affecting children and adults today and in the future. It conceptualises an entire Australian state becoming a single platform to enhance the speed, capacity and connectedness of research. The GenV 2020s Cohort will be open to all 160,000 newborns born over two full years from 2021 and their parents. With consent, it brings together new and existing data and biospecimens across time and generations. This rich fabric can then support diverse methodologies including discovery, trials, registries, geospatial and health services research.

Throughout 2018, GenV was in its conceptualising phase, commencing work on building its prototype data repository, biobank, scientific protocol and ethics submission. An important early activity for GenV's Solutions Hub was to collaboratively develop and prioritise agendas for its Method Cores, considered central to developing GenV to ultimately deliver maximal value.

Methods

To inform GenV's development, the Solutions Hub's earliest activity was to run Research Methodology Brainstorming Sessions in March-May 2018 followed by a survey to prioritise the ideas generated. The sessions mirrored seven of GenV's eight Method Cores as conceptualised at that time, as follows:

- Discovery research & biobanks
- Clinical & registry trials
- Condition-specific databanks
- Population health & learning
- Population trials
- Health services research
- Place-based research

This rapid process aimed to identify high-priority research methodologic features sufficiently early for GenV to enable them during its design development. It was intended to be rapid and non-binding – ie as an early and informal scoping activity to elicit ideas that could maximise GenV's value.

We approached a convenience sample of 64 individuals from Melbourne Children's and Monash Children's campuses, selected for their availability and their knowledge about and experience in research and practice involving mothers' and children's health and wellbeing. Of these, 34 child health and wellbeing experts were available to attend at least one of the seven sessions.

Results

Jointly, 94 discrete possible design features were identified during the seven Brainstorming Sessions. To help GenV prioritise these features, 47 respondents (key experts, GenV Investigator Committee members and GenV Program Management Office team members) rated the feasibility and value-add of each feature via a REDCap survey. Twenty-three of the 94 features appeared in at least one of the 'top 10' rankings (rankings for mean value, mean feasibility, and/or % of respondents who thought a feature both highly feasible and valuable).

The 'Top 5' design features, prioritised in order of mean rated value, were:

(1) Data quality (uptake, standardisation, harmonisation) of existing datasets
(2) Phenotypes (eg BMI, BP, vocabulary)
(3) Identify GenV participant in existing data IDs eg Victorian Student Number, Child Health Record
(4) Social data eg Centrelink, homelessness, child protection data
(5) Consent for mother and father for administrative data to enter GenV.

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Most features were given a rating of either moderate-to-high value and feasibility, or high value but low feasibility. Some features were duplicated across sessions suggesting utility across, not just within, research methodologies. Some of these ideas were already core to GenV's methods while others were novel. All required further scoping.

An unpredicted outcome from this activity was the emergence of themes in these top rated features:

- GenV utilising and improving existing data
- GenV generating and utilising new data
- GenV and research methodologies enhancing each other
- GenV utilising IT applications.

Three further themes emerged in lower ranked features. That they did not appear in the top 10 features most likely reflected the relative lack of biological researchers in the sample:

- GenV utilising and improving existing bio specimens and/or images/traces
- GenV collecting and utilising new bio specimens and/or image/traces and their data
- GenV processes, capabilities and resources.

Limitations of a convenience sample have been considered as GenV has developed. For example, we were aware that some features may not have been identified while others may have been 'valued' more or less had the participant sample differed; therefore, additional ideas have since been incorporated.

Next steps

To realise the full benefit of the Research Methodology Brainstorming Sessions and Survey activity, the GenV team has since undertaken multiple simultaneous activities. These have included:

- **Utilising existing GenV frameworks and prior work** to help prioritise which features to pursue, guided by the GenV Principles
- **Grouping the features into the identified themes** to streamline work processes
- **Convening Method Core Groups**
  - In early 2019, GenV convened small groups for each Method Core and two Focus Areas, each co-led by a GenV investigator and including experts and early career researchers
  - The remit and scope of the Method Core working groups was defined
  - Each Method Core and Focus Area Group has:
    - created an Action Plan informed by GenV's Principles
    - scoped and actioned the prioritised activities
- **Incorporating these activities** into GenV's processes and research plan.

Conclusions

The Research Methodology Brainstorming Sessions and Survey conducted in March-May 2018 rapidly expanded GenV's very early planning to enable highly-valued, feasible research methodologic features within GenV's large cohort framework. Through 2019-20, this translated into GenV design, impact and operational planning led by Method Core Working Groups to enable as many of these features as possible. We thank all participants for offering their time, intellect and lateral thinking so generously.

Overall, the Research Methodology Brainstorming Sessions and Survey findings provided a strong foundation to enhance GenV's potential in highly practical ways. We hope that many of the suggested features come to provide significant value to the research and translational impacts of GenV.

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2. Introduction

2.1 Generation Victoria (GenV)

Generation Victoria's vision is to help solve complex issues affecting children and adults today and in the future. It conceptualises an entire Australian state becoming a single platform to enhance the speed, capacity and connectedness of research. The GenV 2020s Cohort will be open to all 160,000 newborns born over two full years from 2021 and their parents. With consent, it brings together new and existing data and biospecimens across time and generations. This rich fabric can then support diverse methodologies including discovery, trials, registries, geospatial and health services research.

Following a large foundational grant in late 2017, GenV entered its conceptualising phase in early 2018. It commenced work on building its prototype data repository, biobank, scientific protocol and ethics submission. An important early activity for GenV's Solutions Hub was to collaboratively develop and prioritise agendas for its Method Cores, considered central to developing GenV to ultimately deliver maximal value.

2.2 Rationale

During establishment, GenV needed to consider/enable all key research methodology features early in order to avoid subsequent 'missed opportunities'. To this end, the Solutions Hub initially defined eight Method Cores:

- Discovery (fundamental advances in science)
- Clinical & registry trials (management of illness, mental health, special needs)
- Condition-specific databanks (causes and outcomes of wide-ranging problems and illnesses)
- Population health and learning (prevention, prediction, trajectories)
- Population trials (interventions reaching everyone, including the vulnerable)
- Health services research (models for better value, outcomes, efficiency)
- Place-based research (why and how outcomes differ by place and community)
- Digital health (technology transforming health, learning and wellbeing).

Between March-May 2018, the Solutions Hub ran brainstorming sessions for 7 of the 8 Method Cores (not including Digital health, which was felt to be premature). **The groups were tasked with identifying research methodology features that might need to be considered or enabled prior to GenV's commencement for their value to be realised**. Following the sessions, GenV asked participants to rate the feasibility and value-add of each feature using a value-effort matrix.

This activity was not intended to be an exhaustive consultation, but an informal scoping activity that elicited and reality-checked ideas. It aimed to rapidly centre Solutions Hub activities around potential remits of work. Thus, it was acknowledged that, as GenV's planning gained depth, new information would likely change the balance of some initial value-effort matrices.

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3. Methods

3.1 Participants

As research methodologies were the focus of the Brainstorming Sessions, the participants comprised of child health and wellbeing experts with knowledge about and experience in at least one of the seven research methods. There was limited time to complete this work; therefore, most experts were drawn from the Melbourne Children's Campus (Murdoch Children's Research Institute, The Royal Children's Hospital and The University of Melbourne) and Monash Children's campus. The groups were assembled via convenience sampling, a non-probability sampling technique where participants are recruited due to their convenient accessibility, proximity and likely interest. This sampling technique was used in the interests of speed and practicality of the sessions, recognising that this might under-represent some ideas and perspectives but would nonetheless provide a broad starting point from which to grow.

The GenV Operations Management Group (GenV Directors, Program and Stream Managers) and Investigator Committee all suggested diverse potential contributors from their networks. The Solutions Hub emailed invitations to all invitees (see Appendix 1 for wording of initial and reminder emails). In some instances, mostly when they could not attend, invitees nominated other colleagues or team members who they thought could also contribute to the sessions.

3.2 Brainstorming Sessions

Brainstorming Session invitations were sent from 14th March till 19th of April 2018 to 64 scientists and researchers. This invitation included the GenV synopsis, slides of LifeCourse timeline, GenV Principles and GenV priority matrix (please refer to Appendix 1). Invitees replying that they would attend were sent a calendar invitation. One reminder email was sent out 1-7 days prior to the session.

Seven 60-minute Brainstorming Sessions were held during March-May 2018. All sessions were led by GenV Scientific Director Melissa Wake with one other GenV Investigator Committee member expert in that methodology. The sessions commenced with a brief outline of GenV and the session purpose, taking approximately 20 minutes. The remaining time was spent brainstorming ideas with the attendees. Each session was audio-recorded and one GenV team member took notes. Minutes were drawn up following each session and all features were included in a spreadsheet.

3.3 Survey

At the conclusion of each Brainstorming Session, GenV Solutions Hub manager, Sarah Davies, collated the ideas for clarity by removing duplicate ideas and the convenors clarified ideas with attendees if required.

An online REDCap survey (see Appendix 2) was developed to include all 94 identified features and ask participants to indicate "what would be needed to make this a reality". Respondents were asked to nominate how feasible a feature was, from easiest (5) to hardest (1), and its value-add for GenV, from most (5) to least (1) valuable. Features were grouped under the brainstorming group heading that generated a specific idea; ideas independently generated by more than one group therefore appeared under more than one heading. GenV Investigator Committee feedback was incorporated into the final format of the survey.

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The survey was undertaken across 12th June through 1st August 2018. The REDCap link with instructions was sent to 73 people on 18th and 25th May 2018 with reminders on 23rd May and 1st June 2018 (see Appendix 1 for wording of initial and reminder emails). Respondents included the GenV Operations Management Group, GenV Investigator Committee and all Brainstorming Session invitees. We asked respondents to rate all ideas across all groups, but if this was not possible, at a minimum to rate the ideas generated by their own group.

Survey results were collated and presented to the GenV Investigator Committee on the 13th June 2018. This resulted in suggestions for improvement on the data presentation. Presentation of data was further developed with input from GenV biostatistician Karen Lamb and GenV Director Melissa Wake.

3.4 Data analysis

The mean feasibility and mean value of each feature was calculated. The distribution of all features was summarised by plotting the mean feasibility and mean value of each feature on a scatter plot with axes ranging from 1 to 5. The scatter plot was divided into four quadrants: High Feasibility & High Value, High Feasibility & Low Value, Low Feasibility & High Value, and Low Feasibility & Low Value, with scores ≥3 representing "high" and <3 representing "low". The percentage of respondents who thought a feature was both highly feasible and valuable (≥ for both on the 5-point scales) was also calculated.

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4. Results

4.1 Brainstorming Session results

Table 1 presents the total number of people who were invited and attended the Brainstorming Sessions and the total number of features identified during the Brainstorming Sessions. Thirty-four of 67 invitees attended one or more Brainstorming Sessions, with varying numbers (ranging from 4-7) per session. Three people attended more than one session.

Ninety-four features were identified during the Brainstorming Sessions (Appendix 3). Ten of these features were suggested in more than one of the sessions, ie duplicated across different research methodology areas. For example, the feature, 'Hospital EMR data' was suggested in both the 'Clinical & Registry Trials' and 'Condition-specific databanks trials' sessions. The full list of recurring features can be found in Appendix 4.

Table 1: Brainstorming Sessions – total number of people and features

Brainstorming Session	Total invited	Total attended	Number of features identified
Discovery research & biobanks	8	3	18
Clinical & registry trials	12	7	18
Condition-specific databanks	7	5	12
Population health & learning	11	4	18
Population trials	12	4	12
Health services research	11	7	9
Place-based research	6	4	7

4.2 Survey results

Of the 73 people invited to rate ideas from at least one session, 47 (64%) completed at least one of the surveys. Table 2 shows that between 17 and 30 respondents rated each session's ideas.

Table 2: Brainstorming survey respondents

Brainstorming Session	Total invited to complete survey	Total who completed the survey
Discovery research & biobanks	36	27
Clinical & registry trials	42	30
Condition-specific databanks	37	27
Population health & learning	41	29
Population trials	41	30
Health services research	41	29
Place-based research	22	17

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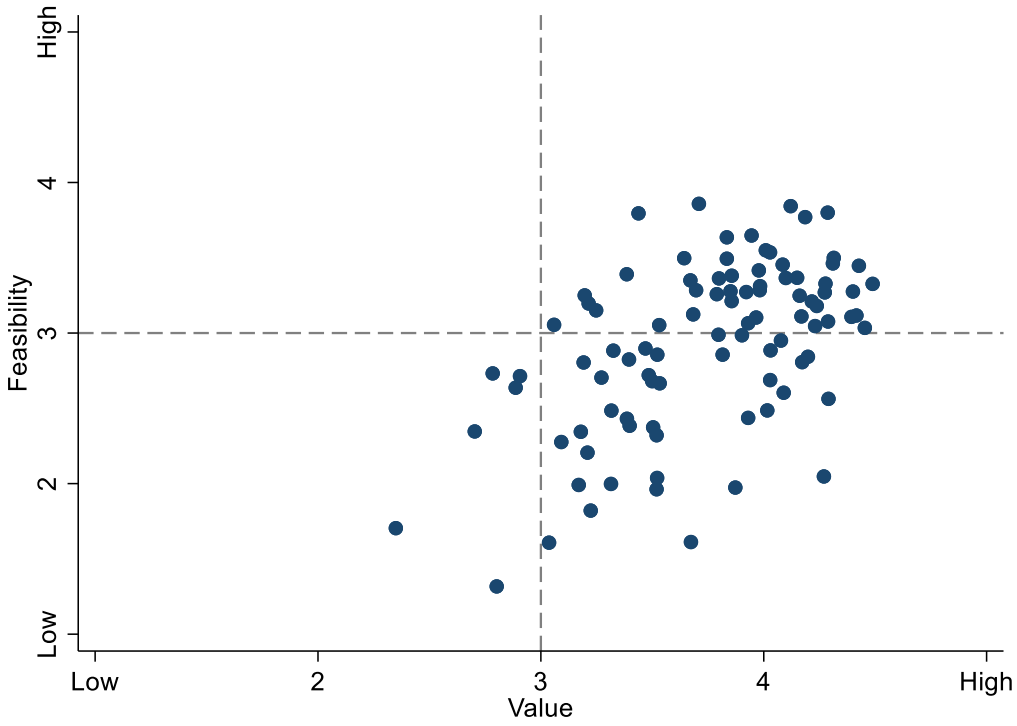
4.2.1 Distribution of ideas by value and feasibility

Figure 1 shows the distribution of all features by mean value and mean feasibility. Of the 94 features, the vast majority fell within quadrant one (high value and high feasibility) and quadrant four (high value but low feasibility). No features fell within quadrant two (high feasibility and low value), and only a small number within quadrant three (low feasibility and low value). Overall, 23 features appeared in at least one of the 'Top 10' tables below for high value, high feasibility, or high value and feasibility.

Figure 1: Value vs feasibility means for all 94 features



4.2.2 Most valued activities

Table 3 shows the top 11 features for mean value. We present the top 11, rather than 10, because the final three features tied on means of 4.25.

Many of the highly-valued features relate to the capacity to collect high-quality administrative, social and phenotypic data, both existing and new. The feature rated most valuable was 'Data quality (uptake, standardisation, and harmonisation) of existing datasets. Where the same ideas were rated more than once because they had been generated by more than one group, ratings were notably similar.

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Table 3: Mean ratings for the 11 features rated most valuable

Brainstorming session	Feature	Value Mean	Corresponding feasibility mean
Clinical & registry trials	Data quality (uptake, standardisation, harmonisation) of existing datasets	4.5	3.1
Clinical & registry trials	Phenotypes (eg BMI, BP, vocabulary) at 6, 11, 16 yrs.	4.4	3.3
Population health & learning	Phenotypes (eg BMI, BP, vocabulary) at 6, 11, 16 yrs.	4.4	3.3
Population Trials	Identify GenV participant in existing data IDs eg Victorian Student Number (VSN) or Child Health Record	4.4	3.2
Clinical & registry trials	Social data eg Centrelink, homelessness, child protection data	4.4	3.5
Population Trials	Consent for mother and father for administrative data to enter GenV	4.3	3.1
Place-based research	Track change in addresses over time (eg for GIS, place-based research)	4.3	2.2
Population Trials	Collect father information	4.3	3.1
Clinical & registry trials	Trials provide data (baseline, outcome) to GenV for GenV participants	4.3	3.7
Health services research	GP visits: Switch on diagnosis field in EMR, improve standardisation	4.3	2.9
Population health & learning	Can GenV help improve existing data sets before/during collection?	4.3	3.4

4.2.3 Most feasible activities

Table 4 shows the top 10 features for mean feasibility. Note that these ratings may not reflect actual feasibility, which in almost all instances was yet to be explored or demonstrated. Respondents were overall less optimistic about feasibility than value.

The feature considered most feasible was 'Australian Hearing data' (from the 'Condition-specific databanks' session). Other feasible features related to two-way exchange of data between GenV and trials, and GenV's potential to include important confounders and surrogate risk markers, to generate risk scores, and to add value to registries by taking them to a case-cohort platform.

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Table 4: Mean ratings for the 10 features rated most feasible

Session	Feature	Feasibility mean	Corresponding value mean
Condition-Specific Databanks	Australian Hearing data	3.9	3.8
Population health & learning	Push digital surveys/on-line Apps direct from GenV eg at each birthday	3.8	3.5
Clinical & registry trials	GenV provides Lifecourse data to trial for GenV participants	3.8	4.2
Population Trials	GenV provides Lifecourse data to trial for GenV participants	3.8	4.2
Clinical & registry trials	Trials provide data (baseline, outcome) to GenV for GenV participants	3.7	4.3
Condition-Specific Databanks	Registry has benefit of GenV as a case cohort study	3.7	4.0
Population health & learning	Can GenV generate risk scores?	3.6	3.8
Population health & learning	Identification of surrogate data sources for risk factors	3.6	3.8
Clinical & registry trials	Potential confounders common across trials	3.6	4.1
Health services research	Apps/mechanisms to push questionnaires	3.5	4.0

4.2.4 Features most frequently rated as both feasible and valuable (≥3)

Overall, 56 features were considered by >60% of respondents to have both feasibility and value of 3 or above (Appendix 3 shows the ratings for all features). Table 5 presents the top 11 features on both feasibility and value, ordered by percentage of respondents.

The feature that was rated highly by the greatest proportion of respondents was 'Investigate options to collaborate with a small number of LGAs to test GenV ideas'. We note, however, that only 9 individuals rated this item. Other features that a large majority of respondents rated highly were: 'provision of potential confounders common across trials/population health' and 'two-way exchange of data with trials.'

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Table 5: Top 11 features by % respondents rating a feature both highly feasible and valuable (≥3)

Section	Feature	N possible respondents	N complete respondents	% high feasible and valuable
Placed-based research	Investigate options to collaborate with a small number of LGAs to test GenV ideas	18	9	100.0
Clinical & registry trials	GenV provides Lifecourse data to trial for GenV participants	30	21	95.2
Clinical & registry trials	Trials provide trial (baseline, outcome) to GenV for GenV participants	30	19	94.7
Population health & learning	Push digital surveys/on-line Apps direct from GenV eg at each birthday	29	17	94.1
Population Trials	GenV provides Lifecourse data to trial for GenV participants	30	16	93.8
Condition-Specific Databanks	Australian Hearing data	27	15	93.3
Condition-Specific Databanks	NDIS data	27	14	92.9
Clinical & registry trials	Social data eg Centrelink, homelessness, child protection data	30	20	90.0
Population health & learning	Can GenV help improve existing data sets before/during collection?	29	20	90.0
Clinical & registry trials	Potential confounders common across trials	30	18	88.9
Population health & learning	Potential confounders common across population health	29	18	88.9

4.2.5 Themes

On reviewing the features some relatively clear themes emerged. Features were then listed under each theme (see Appendix 5).

Four key themes emerged from the 'top 10' results:

- GenV utilising and improving existing data
- GenV generating and utilising new data
- GenV and research methodologies enhancing each other
- GenV utilising IT applications.

Other themes that emerged (but not in the top 10, perhaps reflecting group composition):

- GenV utilising and improving existing biosamples and/or images/traces
- GenV collecting and utilising new biosamples and/or images/traces and their data
- GenV processes, capabilities and resources.

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4.3 Respondent survey comments

At the conclusion of each of the seven survey sections, respondents could provide free-text comments (see Appendix 6). Respondents frequently expressed that they left some items blank because they lacked knowledge and/or did not have a clinical background in the specified method area or feature. For example, one respondent commented, "I have left a lot of "Don't knows" and blanks because I really don't know the areas well enough". Some respondents also indicated that they did not understand what a specific feature was or referred to.

Some respondents made suggestions to consider in the development of GenV. These included: curbing the ambition of GenV's scope, particularly in areas that did not have well-established research aims and/or questions; maximising use of data and samples that are already collected and stored; having dedicated staff who could assist in the collection of cord blood and placental samples; potentially engaging GenV with trials; and piloting GenV to determine the feasibility of proposed features. One respondent suggested that ongoing contact with GenV families could include maintaining contact with their regular health providers, a family member or friends to follow up with if direct contact is lost.

Some respondents' comments related to specific features. After completing the 'Discovery research & biobanks' survey section, one respondent was unsure whether dynamic consent would work as the consent process for GenV. After completing the 'Health services research' section, a number of queries were raised about Health-related quality of life (HRQL) questionnaires, spanning: the most appropriate informant (parents and then children/youth at an appropriate age, GPs, paediatricians); appropriateness for those with chronic health problems and/or disabilities; whether it could be completed via mobile phone push notifications; and whether this would be overly burdensome to families. After completing the 'Place-based research' section, some respondents suggested developing a framework and indicators for community use, and that some key features could be tested with a small number of LGAs.

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5. Discussion

5.1 Summary of key findings

In total, 67 people were invited to attend one or more research methodology Brainstorming Sessions. Of these invitees, 34 people attended and identified 94 potential research methodology features across seven Brainstorming Sessions. Of the 73 people invited to complete at least one of the seven brainstorming surveys, 47 (64%) completed at least one survey. The vast majority of features were given either a rating of high value and high feasibility, or high value but low feasibility.

5.1.1 Top 10 results

In total, 23 of the 94 features appeared in at least one of the 'top 10' results for mean value, mean feasibility, and/or percentage of respondents who rated a feature to be both highly feasible and valuable (Tables 3, 4 & 5). Clinical and registry trials (11) and Population Health and Learning (8) were the two research methodology areas most represented in the 'top 10' results. This may have reflected the convenience nature of the sample, with relatively few laboratory and genetics researchers.

5.1.2 GenV utilising and improving existing data

An emerging theme common across the top 10s related to utilising and improving existing datasets, with an inference that, despite their potential benefit for public-good research, these datasets are traditionally difficult for researchers to access. Australian Hearing, the National Disability Insurance Scheme (NDIS), Victorian Student Number (VSN), Child Health Record and social (eg Centrelink, homelessness, child protection) data were all identified as challenging to access. Respondents thought it would be highly valuable to collect father information and administrative data for both fathers and mothers. They also felt that GenV could contribute to improving data through collection, standardisation and harmonisation. For example, one highly-ranked feature proposed improving standardisation of data collected in General Practices (GP) by ensuring the diagnosis field in GP Electronic Medical Records is always filled.

5.1.3 GenV generating and utilising new data

Generating and utilising new data was another key theme identified in the top 10s. Two very high priority items were the collection of phenotypic data and the ability to track participant addresses over time. Respondents also thought it would be highly feasible for GenV to identify surrogate data sources for risk factors and generate risk scores. It was considered both highly feasible and valuable to identify and/or collect common confounders across trials and population health.

5.1.4 GenV and research methodologies enhancing each other

An interesting theme was the potential for GenV and research methodologies to enhance each other. The capacity for the linking and sharing of participant data in both directions between GenV and trials was rated very highly – ie clinical and registry trials providing trial baseline and outcome data to GenV and, conversely, GenV providing life course data for population, clinical and registry trials. Other themes were the potential for GenV to enrich Condition-specific databanks via case-cohort capabilities, and

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the potential for GenV to collaborate with Local Government Areas to test GenV ideas regarding Place-based research.

5.1.5 GenV utilising IT applications

The final theme focused on IT applications, which were considered to be both highly feasible and valuable (≥3). These IT applications included digital push surveys and online Apps direct from GenV. This theme was accompanied by caution to ensure push requests did not over-burden families.

5.2 Limitations

While the Brainstorming Sessions identified a breadth of features that could maximise GenV's value, there were some limitations. Given the early start-up phase of GenV and the need to kick-start its future translational activities, convenience sampling was used. This quickly identified and recruited a range of experts in child health and wellbeing who had experience in at least one of the seven research methodologies, were easily accessible due to geographical proximity and had a willingness to take part. However, this resulted in all attendees being known to the GenV team or investigator committee, almost all being based on the Melbourne Children's Campus, and under-representation of other experts across the state of Victoria/Australia and of some fields (especially laboratory and genetic experts). Thus, we may have under-identified some features of particular relevance, for example, rural or regional experts, particular vulnerable groups or discovery and genetic research.

The number of experts who were invited (6 to 12) and attended (4 to 7) each GenV Brainstorming Session varied. So too did the numbers of features identified (7 to 18) and of those who were sent surveys (22 to 42) and responded (17 to 30) to the surveys. Thus, some level of bias is likely to have been introduced. For example, the Clinical & Registry trial session had the most number of experts invited to (12) and attend (7) the session and most features identified (18). Clinical & Registry trials also had the most number of features (11 features) appear in the top '10' mean value, mean feasibility and features ordered by percentage of respondents who thought a feature both highly feasible and valuable. However, this is unlikely to have solely reflected numbers. For example, the Health Services Research group also had a high number of invitees (11) and attendees (7) yet only 9 features were identified and only 2 appeared in the top 10 results.

As this early activity focused on research methodology, consumers did not contribute. We cannot say how this may have altered the ideas generated or the value and feasibility ratings. However, consumer input is vital to GenV's planning and has been canvassed via other routes, including extensive prior and subsequent focus groups and small and large parent panel surveys.

5.3 Considerations for GenV

These ideas have directly informed the work plans of the current Method Cores and two life stage Focus Area Groups (Pregnancy, Newborns), which have in turn influenced GenV planning and implementation activities, particularly for the Cohort 2020s and Data Innovation streams. While perceptions of value and feasibility may shift with the evolution of GenV and its stakeholders, the ideas generated are fundamental to maximising GenV's value in ways that are feasible and not over-burdensome. They have also proved robust; while some new ideas have emerged between mid-2018 when this activity was conducted and publication of this report in mid-2020, these have been relatively few.

While the few items rated as low value (<3) were not further considered here, it may be important not to lose sight of them, as some ratings may have reflected the convenience nature of the respondents.

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Work has since proceeded to progress exploration and implementation where feasible of high-value ideas. Some of these ideas were already core to GenV's methods (such as testing whether fathers can be successfully recruited into the Cohort 2020s), but others have required scoping. GenV has used a number of tools to assist in final decisions:

- **Utilise GenV's frameworks and prior work:** All proposed features have been prioritised via the lens of GenV's six guiding principles (Collaboration, Inclusivity, Sustainability, Enhancement, Systematised Processes, Value) and priority framework (value versus effort).
- **Consider group features under themes:** All features under the identified themes were grouped so that features (such as data linkage with different datasets) could be taken forward as a single activity for which overall responsibility and accountability have been allocated.
- **Convene Method Core and Focus Area Groups:** In 2019, Method Core and the two initial life stage Focus Area Working Groups commenced. Each group is co-led by GenV Investigator Committee members, including both senior experts and early career researchers, and is supported by a GenV Solutions Hub convenor. The mix of groups evolved from the original brainstorming groupings to comprise of (at time of publication in July 2020) Trials, Registries, Health Services, Population Health, Bioresources, Geospatial, Place & Community, Pregnancy and Newborns. A further group (Optimising Antibiotics) met twice in 2019.

  Each group has created an Action Plan informed by the GenV principles to help scope the prioritised activities, understand what is required to implement them, and action the prioritised activities. As of July 2020, several are now progressing formal Statements of Intent outlining their broad protocols, which are forming the basis for detailed processes now being operationalised to embed these and other activities in GenV.
- **Incorporate these activities into GenV planning:** The identified themes have created momentum and guided multiple aspects of GenV's ongoing design across its streams, informing for example its Parent Information and Consent Form, data linkage planning, IT research operations, data repository and external communications. Ultimately, this should mean that many of the features identified in the Brainstorming Sessions contribute to solutions leading to better health and wellbeing for children and adults.

6. Conclusion

The Research Methodology Brainstorming Sessions and Survey conducted in mid-2018 rapidly expanded and progressed the understanding of highly-valued research methodologic features during GenV's very early planning. All were considered within a framework of likely feasibility, recognising that ultimate feasibility has depended on a deeper scoping of implementation processes and the current data landscape. In 2019 and 2020, this work translated into GenV design and impact planning led by Method Core working groups, and exploration of many of the concepts with the broader Victorian community. We thank all participants for offering their time, intellect and lateral thinking so generously.

Overall, the Research Methodology Brainstorming Sessions and Survey findings have provided a strong foundation to enhance GenV's potential in very practical ways. Many of the suggested features are on track to being implemented, and should come to provide enormous value to the research and translational impacts of GenV.

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Appendices

Appendix 1: Brainstorming emails and documents sent to respondents and used at sessions

Email 1: Brainstorming Session Example

Dear xxx,

Generation Victoria (GenV) invites you to a one hour Brainstorming Session focusing on "Clinical & Registry Trials".

The session is on Friday the 23rd of March from 10:30 to 11:30am at MCRI.

Melissa Wake and Andrew Davidson will co-lead it.

Design of the GenV 2020 cohort and GenV LifeCourse Data Repository are moving ahead rapidly (please see attached GenV synopsis). To bring forward further groundwork ahead of forming the Solution Hubs (see wheel below) we are holding single Brainstorming Sessions to pre-focus on the methodologies that may be relevant to each Solution Hub. We'd like these sessions to be informal scoping and reality-checking to elicit your ideas.

Key questions include:

1. What key features, specific to each Solution Hub (eg Clinical & Registry Trials), might we need to consider/enable now – to avoid 'missed opportunities'?
2. What would be needed to make these a reality? (timeline, cost, technical – considering the value vs effort matrix)
3. Who is/are the main stakeholders for these features?
4. Are things likely to be on people's wish lists that are wouldn't ever be feasible? How should we deal with these?

In preparation, we attach 4 short documents that we will use during the session:

- GenV synopsis
- Lifecourse timeline
- GenV principles
- GenV priority matrix

As this session is short, we'll need to be dynamic and efficient so are not planning on teleconference or Zoom facilities. We do understand that this may count you out, but if so we would still value your input (via email) on 1-4 above if you have any thoughts. We'll also circulate a summary to invitees for comment and further input, before reporting back on these sessions to the next GenV Investigator Committee meeting hopefully on April 11th.

Please respond to the calendar invite that will follow this email.

Thanks in advance for your interest and input,

Sarah and Melissa

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Email 2: Brainstorming Session Reminder Example

Dear All,

This is a reminder that the Generation Victoria (GenV) one hour brainstorming session focusing on "Place-based research" i**s on next Tuesday the 29th of May from 2.00 to 3.00pm in the Barnes room** at MCRI.

Design of the GenV 2020 cohort and GenV LifeCourse Data Repository are moving ahead rapidly (please see attached GenV synopsis). To bring forward further groundwork ahead of forming the Solutions Hub we are holding single brainstorming sessions to pre-focus on the research methodologies. We'd like these sessions to be informal scoping and reality-checking to elicit your ideas.

Key questions include:

1. What key features, specific to each methodology (eg Place-based research), might we need to consider/enable now – to avoid 'missed opportunities'?

2. What would be needed to make these a reality? (timeline, cost, technical – considering the value vs effort matrix)

3. Who is/are the main stakeholders for these features?

4. Are things likely to be on people's wish lists that are wouldn't ever be feasible? How should we deal with these?

In preparation, we attach 2 short documents that we will use during the session:

- GenV synopsis
- Brainstorming presentation including; Lifecourse timeline, GenV principles & GenV priority matrix

This is the zoom link if you are joining us online https://zoom.us/j/205995471 (also included in the meeting invite)

Thanks in advance for your interest and input,

Sarah and Melissa

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Email 3: Brainstorming Survey

Dear [Respondent],

Following up on the March 2018 GenV Solution Hub Brainstorming Sessions, we write to ask your help over the next week in prioritising the many ideas generated, via the below REDCap survey.

Update:
We held six Brainstorming Sessions about methodologies that may be relevant to GenV. In total 35 people suggested around 85 ideas, beyond the 'base' GenV model of consent, core biosamples and accessing administrative datasets.
This REDCap survey lists the ideas from **Discovery research & biobanks (excludes Non-invasive prenatal test and Newborn Screening), Clinical & registry trials, Condition-Specific Databanks, Population health and learning, Population trials, Health services research**, plus 'what needs to be done' to make it a reality. Some ideas cropped up more than once.

Now, we're asking you to score each idea - we'll then collate and report back. You may not feel qualified to make an informed judgment on all ideas - no one does - but we are still interested in a quick collective view.

Action

1. Please consider each idea in light of the GenV Principles (listed at the top of each REDCap page).
2. Please nominate:
    - how feasible it is, from easiest (5) to hardest (1); and
    - Its value-add for GenV, from most (5) to least (1) valuable. This can be from any viewpoint eg research value, translation value
3. Make any additional comments in the text box(es). Please note that the survey is confidential but identifiable, so we can follow up on any comments.
4. Submit by Friday the 1-June-2018.

SURVEY: GenV Brainstorming Ideas

Many thanks in advance for your help.
Melissa and Sarah
Generation Victoria

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Appendix 2: Brainstorming Survey

REDCap Survey Instructions

Dear [name].
Following up on the March 2018 GenV Solution Hub brainstorming sessions, we write to ask your help over the next week in prioritising the many ideas generated from the [showsection] sessions.
Please consider each idea in light of the GenV Principles: Collaboration, Inclusivity, Sustainability, Enhancement, Systematised processes and Scalability.
Please nominate:
-- how feasible it is, from easiest (5) to hardest (1); and
-- its value-add for GenV, from most (5) to least (1) valuable. This can be from any viewpoint eg research value, translation value.

Please consider each idea in light of the GenV Principles.
1. Collaboration: Build partnerships with researchers, clinicians, policy makers, service providers & the community.
2. Inclusivity: Be inclusive of all partners, participants and data users.
3. Sustainability: Be financially sustainable and utilise existing infrastructure and capabilities.
4. Enhancement: Be low burden to participants and enhance service.
5. Systematised processes: High throughput processes for >100,000 participants
6. Scalability: Design to scale-up.

GenV brainstorming report, 2020-07-21 v1
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REDCap Survey

	Idea	What would need to be done to enter/inform GenV?	Value	Feasible
1	**Discovery research & biobanks (excludes NIPT, NBS)**	(Note: NLP=Natural Language Processing)	**1 (least) 5 (most)**	**1 (hard) 5 (easy)**
I	**Reported clinical data**			
1.1	Foetal ultrasound	Linkage or consented results retrieval; processes to centralise from radiologies, store, access, process eg NLP; ?via Digital Mat Record AIHW		
1.2	Prenatal mother's urine (routine visits - specified times?)	Access to results via linkage to Digital Mat Record (AIHW) + NLP		
1.3	Prenatal mother's blood (12wks, 28 wks, GTT)	Linkage or consented results retrieval; processes to centralise from hosp/private labs, store, access, process eg NLP; ?via Digital Mat Record		
1.4	Prenatal Group B Strep (GBS) swab at 36 wks.	Linkage or consented results retrieval; processes to centralise from hosp/private labs, store, access, process eg NLP; ? via Digital Mat Record		
I	**Digital images/traces**			
1.5	Foetal ultrasounds	Consented image retrieval from radiologists; processes to centralise & store images, access, process & score – likely use neural learning/AI		
I	**Samples**			
1.6	Prenatal mother's urine (multiple routine visits - specified times?)	Consented urine retrieval (c waiver or temp consent) from hosp/ private labs ± clinic rooms; courier/biobank processes; postnatal consent		
1.7	Prenatal maternal blood aliquots (12w, 28w/GTT, 36w)	Consented blood retrieval (c waiver or temp consent) from hosp/private labs; courier/biobank processes; postnatal consent		
1.8	Prenatal maternal blood spot from antenatal blood (12w,28w/GTT, 36w)	Consented blood retrieval (c waiver or temp consent) from hosp/private labs; courier/biobank processes; postnatal consent		
1.9	Prenatal Group B Strep (GBS) swab at 36 wks	Consented swab retrieval (c waiver or temp consent) from hosp/private labs; courier/biobank processes; postnatal consent		
1.10	Cord blood	Subset of birthing hospitals; suites/kits/midwife training/protocols High processing/storage demands; new practice; ?acceptability/time		
1.11	Newborn faeces	Postnatal wards & labs (birthing hospitals, ?subset); suites/kits/midwife training/protocols; processing/storage demands; ?acceptability		
1.12	Chorionic Villous Sample (CVS) testing	Consented CVS retrieval (c waiver or temp consent) from VCGS/RCH; transfer/biobank processes; postnatal consent; small numbers now		
1.13	Placenta	Subset of birthing hospitals; suites/ midwife training/protocols Very high processing/storage demands; new practice; ?acceptability		

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I	**Processes**	Note **assumption**: all assays deferred till cohort is complete rather than in clinical real-time; issue of feedback of results not decided		
1.14	Population GWAS	Access Newborn Blood Spot at VCGS; SNP GWAS chip - sequence & store data; bioinformatics; generate polygenic risk prediction scores; consent		
1.15	Population whole genome sequencing	Access Newborn Blood Spot at VCGS; sequence/bioinformatics; invest in computing; major consent/ethics/feedback demands (eg BabySeq trial)		
1.16	Newborn methylation screening eg Rett, FraX, Prader Willi	Access Newborn Blood Spot at VCGS; methylation screen; definitive genetic test if screen +ve; consent/ethics/feedback considerations		
1.17	Geographic Information System (GIS) Mapping	Maintain reliable addresses throughout + moving dates (much other GenV data won't need this); statewide GIS datasets; expertise, software		
1.18	Dynamic consent	Mostly for rare diseases; ?population feasibility; ?harder for low ses/ NESB; ?technical issues for 100,000+; many want to consent once only		
	Idea	**What needs to be done?**	**Value**	**Feasible**
2	**Clinical & registry trials**		**1 (least) 5 (most)**	**1 (hard) 5 (easy**
I	**Samples**			
2.1	Prenatal Group B Strep (GBS) swab at 36 wks [as per (1)]	Consented swab retrieval (c waiver or temp consent) from hosp/private labs; courier/biobank processes; postnatal consent		
2.2	Mother blood spot after birth	Logistics, consent, kits/protocols, contact time available (15 mins total)		
2.3	Nasal swab eg MRSA, Group A strep	Logistics, consent, willingness, contact time available (15 mins total)		
2.4	Retain serum from all pathology tests in GenV birth band children	Consent; private/hospital labs reliably identify all in age band; activate processes to process, courier/centralise; biorepository processes		
I	**Data common to many trials, not held in existing routine collections**			
2.5	Universal phenotypes (eg BMI, BP, vocabulary) at 6, 11, 16 yrs.	Universal school-based GenV phenotypic waves at 6,11,16 yrs., informed by prior (outcomes) & planned (baseline) studies/trials in 2020 age band		
2.6	Potential confounders common across trials	Scope high-priority confounders in existing data & how to access; scope what GenV could collect and how, within GenV Principles		
2.7	Criteria for selection, stratification (eg BMI, breastfeeding, ses)	See 2.13 below		
I	**Specific data types**			
2.8	Social data eg Centrelink, homelessness, child protection data	Scope federal/state datasets – consented retrieval +/or linked enduring composite datasets held by AIHW (federal), VCDL/VSDIIR (state)		
2.9	Hospital EMR data	Scope EMRs across Victoria (mostly Cerna, Epic); what data may be available & how (governance, quality, natural language processing etc.)		

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2.10	NDIS data	Scope as NDIS datasets develop; ?consented retrieval +/or linkage		
I	**Processes**			
2.11	Data quality (uptake, standardisation, harmonisation) existing datasets	Coalition of users to use and feedback focused need to improve data; ↑ data literacy of service providers; learn from NZ IDI, Canadian ICES, UK		
2.12	GenV provides Lifecourse data to trial for GenV participants	Mechanism for trials to gather consent to obtain GenV data for in-age participants; standardise ethics wordings for GenV age-band children		
2.13	Trials provide data to GenV for GenV participants	Mechanism for GenV to gather consent to obtain future trials data from trials seeking to use GenV data (ie trial and GenV mutually enriched)		
2.14	Non-GenV trial participants join GenV at any age; prior, long term FU	GenV develops consent; trial or GenV administers; trial and GenV mutually enriched (# missing reduced for trials and GenV)		
2.15	GenV identifies individuals meeting trials criteria in real time	Shifts scoring/processing of data to real time - unlikely to be feasible; deferral until each wave complete enhances quality, scope, cost		
2.16	GenV randomises individuals into trials in real time	Major cost/process/ethics: randomisation in real time, consent – competes with focus on best data collection & management		
2.17	Prior exposures (biosamples, data) for children entering registry trials	Major cost/process/ethics: depletable resource used for targeted single assay vs enrichment for whole cohort eg multiple serologies		
2.18	Include trials that test diagnostic validity	Include endpoints (eg phenotypes, 2.5 & 3.2) against which predictive accuracy of new, composite or personalised predictors can be assessed		
	Idea	**What needs to be done?**	**Value**	**Feasible**
3	**Condition-Specific Databanks**		**1 (least) 5 (most)**	**1 (hard) 5 (easy**
I	**Samples**	Consent (new/waiver); provider processes (private, hospital) to process, courier/centralise; biorepository processes to store, assay, access data		
3.1	Cytomegalovirus (CMV) in newborn	1. Saliva by GenV staff at consent, OR 2. From Guthrie collected by midwives using existing blood spot		
I	**Data common to many studies, not held in existing routine collections**			
3.2	Universal phenotypes (eg BMI, BP, vocabulary) at 6, 11, 16 yrs.	Universal school-based GenV phenotypic waves at 6,11,16 yrs., informed by prior (outcomes) & planned (baseline) studies/trials in 2020 age band		
I	**Specific data types**			
3.3	Hospital EMR data	Scope EMRs across Victoria (mostly Cerna, Epic); what data may be available & how (governance, quality, natural language processing etc.)		
3.4	NDIS data	Scope as NDIS datasets develop; ?consented retrieval +/or linkage		
3.5	Australian Hearing data	Scope; ?consented retrieval +/or linkage; governance		

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I	**Processes**	Note **assumption**: all assays deferred till cohort is complete rather than in clinical real-time; issue of feedback of results not decided		
3.6	Population GWAS	Access Newborn Blood Spot at VCGS; SNP GWAS chip - sequence & store data; bioinformatics; generate polygenic risk prediction scores; consent		
3.7	Population whole genome/exome sequencing	Access Newborn Blood Spot at VCGS; sequence/bioinformatics; invest in computing; major consent/ethics/feedback demands (eg BabySeq trial)		
3.8	Microarray	Targeted DNA (gene) or RNA (transcription) probes; unknowns with consent/feedback		
3.9	Broad range of assays for multiple conditions	*GenV team not sure what this means, over and above all the above*		
3.10	Registry has benefit of GenV as a case cohort study	Mechanism for databanks to gather consent to obtain GenV data for in-age participants; standardise ethics for GenV age-band children		
3.11	Capability to link individual registry participants to GenV	GenV develops consent; registry or GenV administers; registry and GenV mutually enriched (# missing reduced for registries and GenV)		
3.12	Nested trial	As for 3.10		
	Idea	**What needs to be done?**	**Value**	**Feasible**
4	**Population health and learning**		**1 (least) 5 (most)**	**1 (hard) 5 (easy**
I	**Data common to many studies, not held in existing routine collections**			
4.1	Universal phenotypes (eg BMI, BP, vocabulary) at 6, 11, 16 yrs.	Universal school-based GenV phenotypic waves at 6,11,16 yrs., informed by prior (outcomes) & planned (baseline) studies/trials in 2020 age band		
4.2	Potential confounders common across population health	Scope high-priority confounders in existing data across multiple sources; how to access; scope how & what GenV could collect, by GenV Principles		
4.3	Risk factors for prevention, early identification and better targeting	Scope high-priority exposures; identify which exist & how to access; for others, scope what GenV could collect and how, within GenV Principles		
4.4	'Push' digital surveys/on-line Apps direct from GenV eg at each birthday	Develop low-burden, high-interest, adaptive Apps/qsts to push to participants on regular schedule – how often? Build in feedback?		
4.5	'Pull' digital data eg participants securely deposit images	Scope burden, timing, feasibility on multiple & ever-changing platforms		
4.6	Providers collect additional Apps/qsts at scheduled visits	Develop low-burden, high-interest, adaptive (high precision) Apps/qsts; GenV funds backfill for additional time, provides Apps and training		
4.7	Internet of Things/wearable devices	Scope with MCRI e-health team, Curve Tomorrow, telcos, google – how?? Acceptability/privacy?		
4.8	Identification of surrogate data sources for risk factors	Scope surrogate data sources for high-priority exposures; how to access; scope how & what GenV could collect, by GenV Principles		
4.9	Can GenV generate risk scores?	Scope existing risk scores in other studies eg polygenic risk scores		

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		NB cannot be done in real time (batch once GenV recruitment complete)		
4.10	Can GenV help improve existing data sets?	Partnerships/support/catalyst to augment data and amend/enhance quality of existing data by 2020; data literacy among service providers;		
4.11	Exposures collected during pregnancy (before GenV consent)	Scope high-priority pregnancy exposures across data sources; how to access; scope how & what GenV could collect, by GenV Principles		
4.12	Geographic Information System (GIS) mapping	Partnerships with GIS experts; scope existing datasets, date-stamp moves; maintain reliable addresses; expertise, software, mapping		
I	**Samples**			
4.13	Blood spot for both parents	Logistics, consent, kits/protocols, contact time available (15 mins total); note that father often not present		
I	**Specific data types**	Consent (new/waiver); processes with all providers/companies to access/transmit/score/store data; may need NLP if in pdf:		
4.14	Include private pathology data	Linkage or consented results retrieval; processes to centralise from private (+hosp) labs; store, access, process eg NLP; ?via Digital Child Recd		
4.15	Include private data sets eg health insurance, Super, groceries	Linkage or consented results retrieval; processes to centralise from sources; store, access, process eg NLP; ?acceptability, breadth of consent		
4.16	Include Nurse on Call, Health Direct data	Linkage or consented results retrieval; unsure if identifiers adequate from these services; store, access, process eg NLP; ?via Digital Child Recd		
4.17	Include social media data eg Facebook, subscriptions to Foxtel/Netflix, large consumer based data, CSIRO social media monitoring	*How would GenV do this? Note recent loss of trust in Facebook et al*		
4.18	GenV collect radiation levels (via receptor boxes in some homes)	*Partnerships with radiation experts to scope – how would GenV do this?*		
	Idea	**What needs to be done?**	**Value**	**Feasible**
5	**Population trials**		**1 (least) 5 (most)**	**1 (hard) 5 (easy**
I	**Specific data types**			
5.1	Identify GenV participant in existing data IDs eg Victorian Student Number (VSN) or Child Health Record	Greatly enhances deterministic linkage/merging; scope current and soon-to-be-current enduring numbers; how would GenV get numbers?		
5.2	Feedback to parents	Basic feedback at GenV specific waves and digital 'push' data collection; otherwise may not be possible/beneficial (as per UK Biobank RCTs)		
I	**Processes**			
5.3	GenV recruits to trials at initial birth consent	Only 15-20 minutes for full consent; how much can be loaded into this? Impact on recruitment to GenV itself?		

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5.4	Select and recruit *within* GenV at later ages	May not be possible – must maintain reliable addresses/contacts at all times; shifts scoring/processing to real time; adds GenV-specific burden		
5.5	GenV provides Lifecourse data to trials for GenV participants	Mechanism for trials to gather consent to obtain GenV data for in-age participants; standardise ethics wordings for GenV age-band children		
5.6	Trials provide data to GenV for in-age participants	Mechanism for GenV to gather consent to obtain future trials data from trials seeking to use GenV data (ie trial and GenV mutually enriched)		
5.7	Collect father information	Most feasible through linked administrative datasets (see below) Test feasibility of consent soon after birth via maternal approach		
5.8	Consent for mother and father for administrative data to enter GenV	May need consent waiver – no current mechanism to reliably contact and consent father		
5.9	Cluster randomised trials eg regions, schools, communities, et al	Trials take place outside GenV in GenV age band, and access individual/summary GenV data		
5.10	Consent of both GenV and population trials need to reflect relationship between GenV and other research	Consent wording by trial and GenV recognises needs of wide range of data sources – will need to be broad		
5.11	Capability to link Individual trial participants to GenV	Explore bidirectional ability to match participants (trials ↔ GenV) – draw on Canadian/Ontarian experience; ethics may be complex		
5.12	How can consent account for unknowns eg new data collections	Make consent broad; trials collect any additional specialised info/data; dynamic consent could cover this but note burden/literacy requirements		
	Idea	**What needs to be done?**	**Value**	**Feasible**
6	**Health services research**		**1 (least) 5 (most)**	**1 (hard) 5 (easy**
I	**Specific data types**			
6.1	GP visits: Switch on diagnosis field in EMR, improve standardisation	GP incentives to complete? Vendors to enhance software? Pop-up for all in-age children?		
6.2	GP visits: add global HRQL/health rating to EMR (E/VG/G/F/P)	GP incentives to complete? Vendors to enhance software? Pop-up for all in-age children?		
6.3	Paediatrician visits: add diagnosis to EMR and improve standardisation	Paed incentives to complete? Vendors to enhance software? Pop-up for all in-age children?		
6.4	Paediatrician visits: add brief HRQL/health rating to EMR (E/VG/G/F/P)	Paed incentives to complete? Vendors to enhance software? Pop-up for all in-age children?		
6.5	ED & hospitalisation: add brief HRQL/health rating to EMR (E/VG/G/F/P)	Hospital incentives to complete? Vendors to enhance software? Pop-up for all in-age children?		
6.6	GenV pushes regular HRQL rating to parent eg quarterly (E/VG/G/F/P)	Single-screen push mechanism to mobile phone - ?acceptability ? How to track mobile phone changes?		
I	**Processes**			
6.7	Apps/mechanisms to push questionnaires	Develop low-burden, high-interest, adaptive Apps/qsts to push to participants on regular schedule – how often? Build in feedback?		

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6.8	Practice change RCTs at GP eg EMR pop-up tailored nudges	GP incentives? Vendors to enhance software? Pop-up for all in-age children? Likely to include some non-GenV participants – problem?		
6.9	GenV links live-time to GP appointment to trigger push or pull mechanism to elicit data or undertake research activity	Live GenV push unlikely to be feasible – but could trigger GP actions/ RCTs for all in-age children with/without waiver, even if not in GenV		
	Idea	**What needs to be done?**	**Value**	**Feasible**
7	**Place-based research**		**1 (least) 5 (most)**	**1 (hard) 5 (easy**
	Specific data types			
7.1	Track change in addresses over time (eg for GIS, place-based research)	Maintain reliable addresses throughout + moving dates (much other GenV data won't need this); statewide GIS datasets; expertise, software; how would one do this for >100,000 children?		
7.2	Extract data out of a community/LGA individual services that do not appear in statewide administrative databases	Likely to require consented retrieval; may require record-by-record manual extraction; may differ LGA by LGA, vs GenV Principle of highly streamlined processes; store, access, process		
7.3	Pre-school attendance data from individual services	Linkage or consented retrieval; processes to centralise from LGAs; store, access, process; ?summary data may be available at state leve l		
7.4	Geographic Information System (GIS) mapping	Partnerships with GIS experts; scope existing datasets, date-stamp moves; maintain reliable addresses; expertise, software, mapping		
l	Processes			
7.	Investigate options to collaborate with a small number of LGAs to test GenV ideas	Build partnerships, attain funding, determine how this meshes with GenV Principle of inclusivity at the state-wide level		
7.	Provide GenV data to communities in an accessible and useful format	Consult communities on type of data and format (eg mapping), scope feasibility of including in GenV; how to access; consider resources required to create data in preferred format		
7.	Develop a framework of indicators, measures and data for community use	Likely to be driven by collaborators rather than GenV itself; consult communities on type of data and format; scope extent to which measures accessible to GenV would meet this need; consider resources required to create data in preferred format		

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Appendix 3: Summary of results for all features by Research Methodology

Section/ Feature	Research Methodology	Feature	Total number of possible respondents	Total number of respondents who responded to both feasibility and value *	Feasible Mean	Value Mean	% high F+V*
1.1	Discovery research & biobanks	Foetal ultrasound results	27	19	2.9	3.6	57.9
1.2	Discovery research & biobanks	Prenatal mother's urine results (routine visits - specified times?)	27	19	3.2	3.2	73.7
1.3	Discovery research & biobanks	Prenatal mother's blood results (12wks, 28 wks., GTT)	27	20	3.1	3.9	70.0
1.4	Discovery research & biobanks	Prenatal Group B Strep (GBS) results at 36 wks.	27	18	3.3	3.2	72.2
1.5	Discovery research & biobanks	Foetal ultrasound images	27	20	2.3	3.3	40.0
1.6	Discovery research & biobanks	Prenatal mother's urine sample (multiple routine visits - specified times?)	27	17	2.5	3.4	35.3
1.7	Discovery research & biobanks	Prenatal maternal blood aliquots from antenatal blood (12wks, 28 wks., glucose tolerance test (GTT), ?3rd trimester)	27	18	2.5	4.1	55.6
1.8	Discovery research & biobanks	Prenatal maternal blood spot from antenatal blood (12wks, 28 wks., glucose tolerance test (GTT), ?3rd trimester)	27	19	2.9	3.6	57.9
1.9	Discovery research & biobanks	Prenatal Group B Strep (GBS) swab at 36 wks.	27	18	2.7	3.0	38.9
1.10	Discovery research & biobanks	Cord blood sample	27	21	2.5	4.2	47.6

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Section/ Feature	Research Methodology	Feature	Total number of possible respondents	Total number of respondents who responded to both feasibility and value *	Feasible Mean	Value Mean	% high F+V*
1.11	Discovery research & biobanks	Newborn faeces	27	19	2.3	3.5	47.4
1.12	Discovery research & biobanks	Chorionic Villous Sample (CVS) sample	27	16	2.7	2.9	31.3
1.13	Discovery research & biobanks	Placental sample	27	18	2.0	3.8	27.8
1.14	Discovery research & biobanks	Population GWAS (genotyping)	27	17	2.9	4.1	64.7
1.15	Discovery research & biobanks	Population whole genome sequencing	27	17	1.7	3.7	23.5
1.16	Discovery research & biobanks	Newborn methylation screening eg Rett, FraX, Prader Willi	27	17	2.9	3.2	58.8
1.17	Discovery research & biobanks	Geographic Information System (GIS) Mapping	27	21	3.4	4.1	76.2
1.18	Discovery research & biobanks	Dynamic consent	27	16	2.8	3.4	75.0
2.1	Clinical & registry trials	Prenatal Group B Strep (GBS) swab at 36 wks. [as per (1)]	30	14	2.8	3.3	57.1
2.2	Clinical & registry trials	Mother blood spot at birth	30	16	2.7	3.4	56.3
2.3	Clinical & registry trials	Nasal swab eg MRSA, Group A strep	30	15	2.7	2.7	40.0
2.4	Clinical & registry trials	Retain serum from all pathology tests in GenV birth band children	30	16	2.5	4.1	56.3
2.5	Clinical & registry trials	Phenotypes (eg BMI, BP, vocabulary) at 6, 11, 16 yrs.	30	21	3.3	4.4	81.0

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Section/ Feature	Research Methodology	Feature	Total number of possible respondents	Total number of respondents who responded to both feasibility and value *	Feasible Mean	Value Mean	% high F+V*
2.6	Clinical & registry trials	Potential confounders common across trials	30	18	3.6	4.1	88.9
2.7	Clinical & registry trials	Criteria for selection, stratification (eg BMI, breastfeeding, ses)	30	21	3.4	4.0	85.7
2.8	Clinical & registry trials	Social data eg Centrelink, homelessness, child protection data	30	20	3.5	4.4	90.0
2.9	Clinical & registry trials	Hospital EMR data	30	21	3.1	4.2	76.2
2.10	Clinical & registry trials	NDIS data	30	16	3.2	4.0	81.3
2.11	Clinical & registry trials	Data quality (uptake, standardisation, harmonisation) existing datasets	30	18	3.1	4.5	72.2
2.12	Clinical & registry trials	GenV provides Lifecourse data to trial for GenV respondents	30	21	3.8	4.2	95.2
2.13	Clinical & registry trials	Trials provide trial (baseline, outcome) to GenV for GenV respondents	30	19	3.7	4.3	94.7
2.14	Clinical & registry trials	Non-GenV trial respondents join GenV at any age; prior, long term FU	30	21	3.3	3.6	66.7
2.15	Clinical & registry trials	GenV identifies individuals meeting trials criteria in real time	30	20	2.1	3.5	20.0
2.16	Clinical & registry trials	GenV randomises individuals into trials in real time	30	18	1.9	3.2	16.7
2.17	Clinical & registry trials	Prior exposures (biosamples, data) for children entering registry trials	30	19	2.8	3.8	52.6
2.18	Clinical & registry trials	Prioritise trials that test diagnostic validity	30	14	3.4	3.8	78.6

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Section/ Feature	Research Methodology	Feature	Total number of possible respondents	Total number of respondents who responded to both feasibility and value *	Feasible Mean	Value Mean	% high F+V*
3.1	Condition-Specific Databanks	Cytomegalovirus (CMV) in newborn	27	17	3.2	3.3	76.5
3.2	Condition-Specific Databanks	Phenotypes (eg BMI, BP, vocabulary) at 6, 11, 16 yrs.	27	19	3.4	4.2	84.2
3.3	Condition-Specific Databanks	Hospital EMR data	27	18	3.3	4.1	83.3
3.4	Condition-Specific Databanks	NDIS data	27	14	3.2	4.0	92.9
3.5	Condition-Specific Databanks	Australian Hearing data	27	15	3.9	3.8	93.3
3.6	Condition-Specific Databanks	Population GWAS (genotyping)	27	17	2.8	4.1	64.7
3.7	Condition-Specific Databanks	Population whole genome/exome sequencing	27	17	2.0	3.6	23.5
3.8	Condition-Specific Databanks	Microarray	27	14	2.5	3.4	21.4
3.9	Condition-Specific Databanks	Broad range of assays for multiple conditions	27	7	3.0	4.0	57.1
3.10	Condition-Specific Databanks	Registry has benefit of GenV as a case cohort study	27	15	3.7	4.0	86.7
3.11	Condition-Specific Databanks	Capability to link individual registry respondents to GenV	27	16	3.4	4.2	81.3
3.12	Condition-Specific Databanks	Nested trial	27	16	3.3	4.2	81.3
4.1	Population health & learning	Phenotypes (eg BMI, BP, vocabulary) at 6, 11, 16 yrs.	29	21	3.3	4.4	85.7

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Section/ Feature	Research Methodology	Feature	Total number of possible respondents	Total number of respondents who responded to both feasibility and value *	Feasible Mean	Value Mean	% high F+V*
4.2	Population health & learning	Potential confounders common across population health	29	18	3.5	4.2	88.9
4.3	Population health & learning	Risk factors for prevention, early identification and better targeting	29	21	3.2	4.2	85.7
4.4	Population health & learning	Push digital surveys/on-line Apps direct from GenV eg at each birthday	29	17	3.8	3.5	94.1
4.5	Population health & learning	Pull digital data eg respondents securely deposit images	29	14	2.9	3.5	64.3
4.6	Population health & learning	Providers collect additional Apps/qsts at scheduled visits	29	16	3.2	3.8	68.8
4.7	Population health & learning	Internet of Things/wearable devices	29	16	2.7	3.4	68.8
4.8	Population health & learning	Identification of surrogate data sources for risk factors	29	15	3.6	3.8	86.7
4.9	Population health & learning	Can GenV generate risk scores?	29	13	3.6	3.8	84.6
4.10	Population health & learning	Can GenV help improve existing data sets before/during collection?	29	20	3.4	4.3	90.0
4.11	Population health & learning	Exposures collected during pregnancy (before GenV consent)	29	22	3.0	4.2	68.2
4.12	Population health & learning	Geographic Information System (GIS) mapping	29	16	3.5	3.7	81.3
4.13	Population health & learning	Blood spot for both parents	29	22	2.5	3.9	45.5
4.14	Population health & learning	Include private pathology data	29	15	2.7	4.0	60.0

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Section/ Feature	Research Methodology	Feature	Total number of possible respondents	Total number of respondents who responded to both feasibility and value *	Feasible Mean	Value Mean	% high F+V*
4.15	Population health & learning	Include private data sets eg health insurance, Super, groceries	29	15	2.3	3.1	40.0
4.16	Population health & learning	Include Nurse on Call, Health Direct data	29	14	2.9	3.1	50.0
4.17	Population health & learning	Include social media data eg Facebook, subscriptions to Foxtel/Netflix, large consumer based data, CSIRO social media monitoring	29	15	1.7	2.4	6.7
4.18	Population health & learning	GenV collect radiation levels (via receptor boxes in some homes)	29	11	2.3	2.7	36.4
5.1	Population Trials	Identify GenV respondent in existing data IDs eg Victorian Student Number (VSN) or Child Health Record	30	16	3.2	4.4	68.8
5.2	Population Trials	Feedback to parents	30	17	3.3	3.4	70.6
5.3	Population Trials	GenV recruits to trials at initial birth consent	30	19	2.5	3.4	36.8
5.4	Population Trials	Select and recruit within GenV at later ages	30	17	3.0	3.9	64.7
5.5	Population Trials	GenV provides Lifecourse data to trial for GenV respondents	30	16	3.8	4.2	93.8
5.6	Population Trials	Trial provides data to GenV for in-age respondents	30	18	3.4	3.8	77.8
5.7	Population Trials	Collect father information	30	19	3.1	4.3	63.2
5.8	Population Trials	Consent for mother and father for administrative data to enter GenV	30	15	3.1	4.3	73.3
5.9	Population Trials	Cluster randomised trials eg regions, schools, communities, et al	30	16	3.2	3.9	68.8

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Section/ Feature	Research Methodology	Feature	Total number of possible respondents	Total number of respondents who responded to both feasibility and value *	Feasible Mean	Value Mean	% high F+V*
5.10	Population Trials	Consent of both GenV and population trials need to reflect relationship between GenV and other research	30	15	3.3	3.8	80.0
5.11	Population Trials	Capability to link Individual trial respondents to GenV	30	16	2.9	3.9	68.8
5.12	Population Trials	How can consent account for unknowns eg new data collections	30	18	3.1	4.1	66.7
6.1	Health services research	GP visits: Switch on diagnosis field in EMR, improve standardisation	29	20	2.9	4.3	65.0
6.2	Health services research	GP visits: add global HRQL/health rating to EMR (E/VG/G/F/P)	29	17	2.3	3.6	52.9
6.3	Health services research	Paediatrician visits: add diagnosis to EMR and improve standardisation	29	14	2.9	4.1	70.0
6.4	Health services research	Paediatrician visits: add brief HRQL/health rating to EMR (E/VG/G/F/P)	29	16	2.6	3.5	56.3
6.5	Health services research	ED & hospitalisation: add brief HRQL/health rating to EMR (E/VG/G/F/P)	29	18	2.6	3.5	50.0
6.6	Health services research	GenV pushes regular eg 3 monthly HRQL rating to parent for self and child (E/VG/G/F/P)	29	18	3.1	3.7	61.1
6.7	Health services research	Apps/mechanisms to push questionnaires	29	19	3.5	4.0	84.2
6.8	Health services research	Subtle pop-ups in GP surgery	29	14	1.9	3.2	35.7

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Section/ Feature	Research Methodology	Feature	Total number of possible respondents	Total number of respondents who responded to both feasibility and value *	Feasible Mean	Value Mean	% high F+V*
6.9	Health services research	GenV links live-time to GP appointment to trigger push or pull mechanism to elicit data or undertake research activity	29	12	1.7	3.0	8.3
7.1	Place-based research	Track change in addresses over time (eg for GIS, place-based research)	18	11	2.2	4.3	27.3
7.2	Place-based research	Extract data out of a community/LGA individual services that do not appear in statewide administrative databases	18	9	1.2	2.8	0.0
7.3	Place-based research	Pre-school attendance data from individual services	18	10	2.0	3.4	20.0
7.4	Place-based research	Geographic Information System (GIS) mapping	18	11	3.3	4.2	72.7
7.5	Place-based research	Investigate options to collaborate with a small number of LGAs to test GenV ideas	18	9	3.3	3.9	100.0
7.6	Place-based research	Provide GenV data to communities in an accessible and useful format	18	9	3.3	3.8	55.6
7.7	Place-based research	Develop a framework of indicators, measures and data for community use	18	7	2.4	3.1	42.9

*omitting missing and don't know

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Appendix 4: Duplicate features

- **Feature**: Prenatal Group B Strep (GBS) swab at 36 wks.
- **Brainstorming Sessions duplicated in:** Discovery research & biobanks and Clinical & Registry Trials

	Q1.9	Q2.1
% high F+V	38.9%	57.1%
Mean Feasibility	2.7	2.8
Mean Value	3.0	3.3

- **Feature:** Population GWAS (genotyping)
- **Brainstorming Sessions duplicated in:** Discovery research & biobanks and Condition-specific databanks

	Q1.14	Q3.6
% high F+V	64.7%	64.7%
Mean Feasibility	2.9	2.8
Mean Value	4.0	4.1

- **Features**: Population whole genome sequencing & Population whole genome/exome sequencing
- **Brainstorming Sessions duplicated in:** Discovery research & biobanks and Condition-specific databanks

	Q1.15	Q3.7
% high F+V	23.5%	23.5%
Mean Feasibility	1.7	2.0
Mean Value	3.7	3.6

- **Feature**: Geographic Information System (GIS) Mapping 1.17 & 4.12
- **Brainstorming Sessions duplicated in:** Discovery research & biobanks and Population health & learning

	Q1.17	Q4.12
% high F+V	76.2%	81.3%
Mean Feasibility	3.4	3.5
Mean Value	4.0	3.7

- **Feature**: Phenotypes (eg BMI, BP, vocabulary) at 6, 11, 16 yrs.
- **Brainstorming Sessions duplicated in:** Clinical & Registry Trials, Condition-specific databanks and Population health & learning

	Q2.5	Q3.2	Q4.1
% high F+V			
Mean Feasibility	3.3	3.4	3.3
Mean Value	4.4	4.2	4.4

- **Feature**: Potential confounders common across trials & Potential confounders common across population health
- **Brainstorming Sessions duplicated in:** Clinical & Registry Trials and Population health & learning

	Q2.6	Q4.2
% high F+V	88.9%	88.9%
Mean Feasibility	3.6	3.5
Mean Value	4.1	4.2

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- **Feature**: Hospital EMR data
- **Brainstorming Sessions duplicated in:** Clinical & Registry Trials and Condition-specific databanks

	Q2.9	Q3.3
% high F+V	76.2%	83.3%
Mean Feasibility	3.1	3.3
Mean Value	4.5	4.1

- **Feature**: NDIS data
- **Brainstorming Sessions duplicated in:** Clinical & Registry Trials and Condition-specific databanks

	Q2.10	Q3.4
% high F+V	81.3%	92.9%
Mean Feasibility	3.2	3.2
Mean Value	4.0	4.0

- **Feature**: GenV provides Lifecourse data to trial for GenV participants
- **Brainstorming Sessions duplicated in:** Clinical & Registry Trials and Population Trials

	Q2.12	Q5.5
% high F+V	95.2%	93.8%
Mean Feasibility	3.8	3.8
Mean Value	4.2	4.2

- **Feature**: Capability to link individual registry participants to GenV
- **Brainstorming Sessions duplicated in:** Condition-specific databanks and Population Trials

	Q3.11	Q5.11
% high F+V	81.3%	68.8%
Mean Feasibility	3.8	2.9
Mean Value	4.2	3.9

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Appendix 5: Features ordered in themes

Item #	Research Method	Feature	What would need to be done to enter/inform GenV?	Possible N	Actual N	Feasible Mean	Value Mean	% high F+V*	Exists	Kept	Centralised
GenV utilising and improving existing data											
1.1	Discovery & biobanks	Foetal ultrasound results	Linkage or consented results retrieval; processes to centralise from radiologies, store, access, process eg NLP; ?via Digital Mat Record AIHW	27	19	2.9	3.6	57.9	I	I	
1.2	Discovery & biobanks	Prenatal mother's urine results	Access to results via linkage to Digital Mat Record (AIHW) + NLP	27	19	3.2	3.2	73.7	I	I	
1.3	Discovery & biobanks	Prenatal mother's blood results	Linkage or consented results retrieval; processes to centralise from hosp/private labs, store, access, process eg NLP; ?via Digital Mat Record	27	20	3.1	3.9	70.0	I	I	
1.4	Discovery & biobanks	Prenatal Group B Strep (GBS) results	Linkage or consented results retrieval; processes to centralise from hosp/private labs, store, access, process eg NLP; ? via Digital Mat Record	27	18	3.3	3.2	72.2	I	I	
1.17	Discovery & biobanks	Geographic Information System (GIS) Mapping	Maintain reliable addresses throughout + moving dates (much other GenV data won't need this); statewide GIS datasets; expertise, software	27	21	3.4	4.1	76.2			
2.6	Registry trials	Potential confounders common across trials	Scope high-priority confounders in existing data & how to access; scope what GenV could collect and how, within GenV Principles	30	18	3.6	4.1	88.9	Varies	Varies	Varies
2.8	Registry trials	Social data	Scope federal/state datasets – consented retrieval +/or linked enduring composite datasets held by AIHW (federal), VCDL/VSDIIR (state)	30	20	3.5	4.4	90.0	I	I	I
2.9	Registry trials	Hospital EMR data	Scope EMRs across Victoria (mostly Cerna, Epic); what data may be available & how (governance, quality, natural language processing etc.)	30	21	3.1	4.2	76.2	I	I	

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Item #	Research Method	Feature	What would need to be done to enter/inform GenV?	Possible N	Actual N	Feasible Mean	Value Mean	% high F+V*	Exists	Kept	Centralised
2.10	Registry trials	NDIS data	Scope as NDIS datasets develop; ?consented retrieval +/or linkage	30	16	3.2	4.0	81.3	I	?	
2.11	Registry trials	Data quality existing datasets	Coalition of users to use and feed back focused need to improve data; ↑ data literacy of service providers; learn from NZ IDI, Canadian ICES, UK	30	18	3.1	4.5	72.2			
3.3	Databanks	Hospital EMR data	Scope EMRs across Victoria (mostly Cerna, Epic); what data may be available & how (governance, quality, natural language processing etc.)	27	18	3.3	4.1	83.3	I	I	
3.4	Databanks	NDIS data	Scope as NDIS datasets develop; ?consented retrieval +/or linkage	27	14	3.2	4.0	92.9	I	?	
3.5	Databanks	Australian Hearing data	Scope; ?consented retrieval +/or linkage; governance	27	15	3.9	3.8	93.3	I	I	
3.11	Databanks	Capability to link individual registry participants to GenV	GenV develops consent; registry or GenV administers; registry and GenV mutually enriched (# missing reduced for registries and GenV)	27	16	3.4	4.2	81.3			
4.2	Population health	Potential confounders common across population health	Scope high-priority confounders in existing data across multiple sources; how to access; scope how & what GenV could collect, by GenV Principles	29	18	3.5	4.2	88.9	Varies	Varies	
4.3	Population health	Risk factors for prevention, early identification and better targeting	Scope high-priority exposures; identify which exist & how to access; for others, scope what GenV could collect and how, within GenV Principles	29	21	3.2	4.2	85.7	Varies	Varies	
4.8	Population health	Identification of surrogate data sources for risk factors	Scope surrogate data sources for high-priority exposures; how to access; scope how & what GenV could collect, by GenV Principles	29	15	3.6	3.8	86.7	I	I	Varies
4.10	Population health	Can GenV help improve existing data sets before/during collection?	Partnerships/support/catalyst to augment data and amend/enhance quality of existing data by 2020; data literacy among service providers;	29	20	3.4	4.3	90.0	I	Varies	Varies

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Item #	Research Method	Feature	What would need to be done to enter/inform GenV?	Possible N	Actual N	Feasible Mean	Value Mean	% high F+V*	Exists	Kept	Centralised
4.11	Population health	Exposures collected during pregnancy	Scope high-priority pregnancy exposures across data sources; how to access; scope how & what GenV could collect, by GenV Principles	29	22	3.0	4.2	68.2	I	Varies	Varies
4.12	Population health	Geographic Information System (GIS) mapping	Partnerships with GIS experts; scope existing datasets, date-stamp moves; maintain reliable addresses; expertise, software, mapping	29	16	3.5	3.7	81.3	I	I	Varies
4.14	Population health	Include private pathology data	Linkage or consented results retrieval; processes to centralise from private (+hosp) labs; store, access, process eg NLP; ?via Digital Child Recd	29	15	2.7	4.0	60.0	I	I	
4.15	Population health	Include private data sets	Linkage or consented results retrieval; processes to centralise from sources; store, access, process eg NLP; ?acceptability, breadth of consent	29	15	2.3	3.1	40.0	I	I	
4.16	Population health	Include Nurse on Call, Health Direct data	Linkage or consented results retrieval; unsure if identifiers adequate from these services; store, access, process eg NLP; ?via Digital Child Recd	29	14	2.9	3.1	50.0	I	I	
4.17	Population health	Include social media data	*How would GenV do this? Note recent loss of trust in Facebook et al*	29	15	1.7	2.4	6.7	I	I	
5.1	Population Trials	Identify GenV respondent in existing data IDs	Greatly enhances deterministic linkage/merging; scope current and soon-to-be-current enduring numbers; how would GenV get numbers?	30	16	3.2	4.4	68.8			
5.7	Population Trials	Collect father information	Most feasible through linked administrative datasets (see below) Test feasibility of consent soon after birth via maternal approach	30	19	3.1	4.3	63.2			
6.1	Health services	GP visits: Switch on diagnosis field in EMR, improve standardisation	GP incentives to complete? Vendors to enhance software? Pop-up for all in-age children?	29	20	2.9	4.3	65.0	I		
6.3	Health services	Paediatrician visits: add diagnosis to EMR	Paed incentives to complete? Vendors to enhance software? Pop-up for all in-age children?	29	14	2.9	4.1	70.0	I		

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Item #	Research Method	Feature	What would need to be done to enter/inform GenV?	Possible N	Actual N	Feasible Mean	Value Mean	% high F+V*	Exists	Kept	Centralised
		and improve standardisation									
6.9	Health services	GenV links live-time to GP appointment to trigger push or pull mechanism to elicit data or undertake research activity	Live GenV push unlikely to be feasible – but could trigger GP actions/ RCTs for all in-age children with/without waiver, even if not in GenV	29	12	1.7	3.0	8.3			
7.1	Place-based	Track change in addresses over time	Maintain reliable addresses throughout + moving dates (much other GenV data won't need this); statewide GIS datasets; expertise, software; how would one do this for >100,000 children?	18	11	2.2	4.3	27.3			
7.2	Place-based	Extract data out of a community/LGA individual services that do not appear in statewide administrative databases	Likely to require consented retrieval; may require record-by-record manual extraction; may differ LGA by LGA, vs GenV Principle of highly streamlined processes; store, access, process	18	9	1.2	2.8	0.0	I	I	
7.3	Place-based	Pre-school attendance data from individual services	Linkage or consented retrieval; processes to centralise from LGAs; store, access, process; ?summary data may be available at state level	18	10	2.0	3.4	20.0	I	I	
7.4	Place-based	Geographic Information System (GIS) mapping	Partnerships with GIS experts; scope existing datasets, date-stamp moves; maintain reliable addresses; expertise, software, mapping	18	11	3.3	4.2	72.7	I	I	Varies
GenV generating and utilising new data											
2.5	Registry trials	Phenotypes at 6, 11, 16 yrs.	Universal school-based GenV phenotypic waves at 6,11,16 yrs., informed by prior (outcomes) & planned (baseline) studies/trials in 2020 age band	30	21	3.3	4.4	81.0			

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Item #	Research Method	Feature	What would need to be done to enter/inform GenV?	Possible N	Actual N	Feasible Mean	Value Mean	% high F+V*	Exists	Kept	Centralised
3.2	Databanks	Phenotypes at 6, 11, 16 yrs.	Universal school-based GenV phenotypic waves at 6,11,16 yrs., informed by prior (outcomes) & planned (baseline) studies/trials in 2020 age band	27	19	3.4	4.2	84.2			
4.1	Population health	Phenotypes at 6, 11, 16 yrs.	Universal school-based GenV phenotypic waves at 6,11,16 yrs., informed by prior (outcomes) & planned (baseline) studies/trials in 2020 age band	29	21	3.3	4.4	85.7			
4.3	Population health	Risk factors for prevention, early identification and better targeting	Scope high-priority exposures; identify which exist & how to access; for others, scope what GenV could collect and how, within GenV Principles	29	21	3.2	4.2	85.7	Varies	Varies	
4.18	Population health	GenV collect radiation levels	*Partnerships with radiation experts to scope – how would GenV do this?*	29	11	2.3	2.7	36.4	I	I	
4.8	Population health	Identification of surrogate data sources for risk factors	Scope surrogate data sources for high-priority exposures; how to access; scope how & what GenV could collect, by GenV Principles	29	15	3.6	3.8	86.7	I	I	Varies
4.9	Population health	Can GenV generate risk scores?	Scope existing risk scores in other studies eg polygenic risk scores NB cannot be done in real time (batch once GenV recruitment complete)	29	13	3.6	3.8	84.6			
6.2	Health services	GP visits: add global HRQL/health rating to EMR (E/VG/G/F/P)	GP incentives to complete? Vendors to enhance software? Pop-up for all in-age children?	29	17	2.3	3.6	52.9			
6.4	Health services	Paediatrician visits: add brief HRQL/health rating to EMR (E/VG/G/F/P)	Paed incentives to complete? Vendors to enhance software? Pop-up for all in-age children?	29	16	2.6	3.5	56.3			
6.5	Health services	ED & hospitalisation: add brief HRQL/health rating to EMR (E/VG/G/F/P)	Hospital incentives to complete? Vendors to enhance software? Pop-up for all in-age children?	29	18	2.6	3.5	50.0			

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Item #	Research Method	Feature	What would need to be done to enter/inform GenV?	Possible N	Actual N	Feasible Mean	Value Mean	% high F+V*	Exists	Kept	Centralised
7.6	Place-based	Provide GenV data to communities in an accessible and useful format	Consult communities on type of data and format (eg mapping), scope feasibility of including in GenV; how to access; consider resources required to create data in preferred format	18	9	3.3	3.8	55.6			
7.7	Place-based	Develop a framework of indicators, measures and data for community use	Likely to be driven by collaborators rather than GenV itself; consult communities on type of data and format; scope extent to which measures accessible to GenV would meet this need; consider resources required to create data in preferred format	18	7	2.4	3.1	42.9			
GenV and research methodologies enhancing each other											
2.12	Registry trials	GenV provides Lifecourse data to trial for GenV participants	Mechanism for trials to gather consent to obtain GenV data for in-age participants; standardise ethics wordings for GenV age-band children	30	21	3.8	4.2	95.2			
2.13	Registry trials	Trials provide trial (baseline, outcome) to GenV for GenV participants	Mechanism for GenV to gather consent to obtain future trials data from trials seeking to use GenV data (ie trial and GenV mutually enriched)	30	19	3.7	4.3	94.7			
2.15	Registry trials	GenV identifies individuals meeting trials criteria in real time	Shifts scoring/processing of data to real time - unlikely to be feasible; deferral until each wave complete enhances quality, scope, cost	30	20	2.1	3.5	20.0			
2.16	Registry trials	GenV randomises individuals into trials in real time	Major cost/process/ethics: randomisation in real time, consent – competes with focus on best data collection & management	30	18	1.9	3.2	16.7			
2.17	Registry trials	Prior exposures for children entering registry trials	Major cost/process/ethics: depletable resource used for targeted single assay vs enrichment for whole cohort eg multiple serologies	30	19	2.8	3.8	52.6			
2.18	Registry trials	Prioritise trials that test diagnostic validity	Include endpoints (eg phenotypes, 2.5 & 3.2) against which predictive accuracy of new, composite or personalised predictors can be assessed	30	14	3.4	3.8	78.6			

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Item #	Research Method	Feature	What would need to be done to enter/inform GenV?	Possible N	Actual N	Feasible Mean	Value Mean	% high F+V*	Exists	Kept	Centralised
3.10	Databanks	Registry has benefit of GenV as a case cohort study	Mechanism for databanks to gather consent to obtain GenV data for in-age participants; standardise ethics for GenV age-band children	27	15	3.7	4.0	86.7			
3.11	Databanks	Capability to link individual registry participants to GenV	GenV develops consent; registry or GenV administers; registry and GenV mutually enriched (# missing reduced for registries and GenV)	27	16	3.4	4.2	81.3			
3.12	Databanks	Nested trial	As for 3.10	27	16	3.3	4.2	81.3			
5.3	Population Trials	GenV recruits to trials at initial birth consent	Only 15-20 minutes for full consent; how much can be loaded into this? Impact on recruitment to GenV itself?	30	19	2.5	3.4	36.8			
5.5	Population Trials	GenV provides Lifecourse data to trial for GenV participants	Mechanism for trials to gather consent to obtain GenV data for in-age participants; standardise ethics wordings for GenV age-band children	30	16	3.8	4.2	93.8			
5.6	Population Trials	Trial provides data to GenV for in-age participants	Mechanism for GenV to gather consent to obtain future trials data from trials seeking to use GenV data (ie trial and GenV mutually enriched)	30	18	3.4	3.8	77.8			
5.9	Population Trials	Cluster randomised trials	Trials take place outside GenV in GenV age band, and access individual/summary GenV data	30	16	3.2	3.9	68.8			
5.11	Population Trials	Capability to link Individual trial participants to GenV	Explore bidirectional ability to match participants (trials ↔ GenV) – draw on Canadian/Ontarian experience; ethics may be complex	30	16	2.9	3.9	68.8			
7.6	Place-based	Provide GenV data to communities in an accessible and useful format	Consult communities on type of data and format (eg mapping), scope feasibility of including in GenV; how to access; consider resources required to create data in preferred format	18	9	3.3	3.8	55.6			
GenV utilising IT applications											

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Item #	Research Method	Feature	What would need to be done to enter/inform GenV?	Possible N	Actual N	Feasible Mean	Value Mean	% high F+V*	Exists	Kept	Centralised
4.4	Population health	Push digital surveys/on-line Apps direct from GenV	Develop low-burden, high-interest, adaptive Apps/qsts to push to participants on regular schedule – how often? Build in feedback?	29	17	3.8	3.5	94.1			
4.5	Population health	Pull digital data	Scope burden, timing, feasibility on multiple & ever-changing platforms	29	14	2.9	3.5	64.3			
4.6	Population health	Providers collect additional Apps/qsts at scheduled visits	Develop low-burden, high-interest, adaptive (high precision) Apps/qsts; GenV funds backfill for additional time, provides Apps and training	29	16	3.2	3.8	68.8			
4.7	Population health	Internet of Things/ wearable devices	Scope with MCRI e-health team, Curve Tomorrow, telcos, google – how?? Acceptability/privacy?	29	16	2.7	3.4	68.8			
6.6	Health services	GenV pushes regular	Single-screen push mechanism to mobile phone - ? Acceptability? How to track mobile phone changes?	29	18	3.1	3.7	61.1			
6.7	Health services	Apps/mechanisms to push questionnaires	Develop low-burden, high-interest, adaptive Apps/qsts to push to participants on regular schedule – how often? Build in feedback?	29	19	3.5	4.0	84.2			
GenV utilising and improving existing bio specimens and/or images/traces											
1.5	Discovery & biobanks	Foetal ultrasound images	Consented image retrieval from radiologists; processes to centralise & store images, access, process & score – likely use neural learning/AI	27	20	2.3	3.3	40.0	I	I	
1.6	Discovery & biobanks	Prenatal mother's urine sample	Consented urine retrieval (c waiver or temp consent) from hosp/ private labs ± clinic rooms; courier/biobank processes; postnatal consent	27	17	2.5	3.4	35.3	I		
1.7	Discovery & biobanks	Prenatal maternal blood aliquots from antenatal blood	Consented blood retrieval (c waiver or temp consent) from hosp/private labs; courier/biobank processes; postnatal consent	27	18	2.5	4.1	55.6	I		
1.8	Discovery & biobanks	Prenatal maternal blood spot from antenatal blood	Consented blood retrieval (c waiver or temp consent) from hosp/private labs; courier/biobank processes; postnatal consent	27	19	2.9	3.6	57.9			

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Item #	Research Method	Feature	What would need to be done to enter/inform GenV?	Possible N	Actual N	Feasible Mean	Value Mean	% high F+V*	Exists	Kept	Centralised
1.9	Discovery & biobanks	Prenatal Group B Strep (GBS) swab at 36 wks.	Consented swab retrieval (c waiver or temp consent) from hosp/private labs; courier/biobank processes; postnatal consent	27	18	2.7	3.0	38.9	I	?	
1.12	Discovery & biobanks	Chorionic Villous Sample (CVS) sample	Consented CVS retrieval (c waiver or temp consent) from VCGS/RCH; transfer/biobank processes; postnatal consent; small numbers now	27	16	2.7	2.9	31.3	I	?	I
1.16	Discovery & biobanks	Newborn methylation screening	Access Newborn Blood Spot at VCGS; methylation screen; definitive genetic test if screen +ve; consent/ethics/feedback considerations	27	17	2.9	3.2	58.8	I		
2.1	Registry trials	Prenatal Group B Strep (GBS) swab at 36 wks.	Consented swab retrieval (c waiver or temp consent) from hosp/private labs; courier/biobank processes; postnatal consent	30	14	2.8	3.3	57.1	I	?	
2.4	Registry trials	Retain serum from all pathology tests in GenV birth band children	Consent; private/hospital labs reliably identify all in age band; activate processes to process, courier/centralise; biorepository processes	30	16	2.5	4.1	56.3	I		
3.6	Databanks	Population GWAS (genotyping)	Access Newborn Blood Spot at VCGS; SNP GWAS chip - sequence & store data; bioinformatics; generate polygenic risk prediction scores; consent	27	17	2.8	4.1	64.7			
3.7	Databanks	Population whole genome/exome sequencing	Access Newborn Blood Spot at VCGS; sequence/bioinformatics; invest in computing; major consent/ethics/feedback demands (eg BabySeq trial)	27	17	2.0	3.6	23.5			
GenV collecting and utilising new bio specimens and/or image/traces and their data											
1.10	Discovery & biobanks	Cord blood sample	Subset of birthing hospitals; suites/kits/midwife training/protocols High processing/storage demands; new practice; ?acceptability/time	27	21	2.5	4.2	47.6			
1.11	Discovery & biobanks	Newborn faeces	Postnatal wards & labs (birthing hospitals, ?subset); suites/kits/midwife training/protocols; processing/storage demands; ?acceptability	27	19	2.3	3.5	47.4			

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Item #	Research Method	Feature	What would need to be done to enter/inform GenV?	Possible N	Actual N	Feasible Mean	Value Mean	% high F+V*	Exists	Kept	Centralised
1.13	Discovery & biobanks	Placental sample	Subset of birthing hospitals; suites/ midwife training/protocols Very high processing/storage demands; new practice; ?acceptability	27	18	2.0	3.8	27.8			
1.14	Discovery & biobanks	Population GWAS (genotyping)	Access Newborn Blood Spot at VCGS; SNP GWAS chip - sequence & store data; bioinformatics; generate polygenic risk prediction scores; consent	27	17	2.9	4.1	64.7			
1.15	Discovery & biobanks	Population whole genome sequencing	Access Newborn Blood Spot at VCGS; sequence/bioinformatics; invest in computing; major consent/ethics/feedback demands (eg BabySeq trial)	27	17	1.7	3.7	23.5			
2.2	Registry trials	Mother blood spot at birth	Logistics, consent, kits/protocols, contact time available (15 mins total)	30	16	2.7	3.4	56.3			
2.3	Registry trials	Nasal swab	Logistics, consent, willingness, contact time available (15 mins total)	30	15	2.7	2.7	40.0			
3.1	Databanks	Cytomegalovirus (CMV) in newborn	Saliva by GenV staff at consent, OR From Guthrie collected by midwives using existing blood spot	27	17	3.2	3.3	76.5			
3.8	Databanks	Microarray	Targeted DNA (gene) or RNA (transcription) probes; unknowns with consent/feedback	27	14	2.5	3.4	21.4			
3.9	Databanks	Broad range of assays for multiple conditions	*GenV team not sure what this means, over and above all the above*	27	7	3.0	4.0	57.1			
4.13	Population health	Blood spot for both parents	Logistics, consent, kits/protocols, contact time available (15 mins total); note that father often not present	29	22	2.5	3.9	45.5			
GenV processes, capabilities and resources											
1.18	Discovery & biobanks	Dynamic consent	Mostly for rare diseases; ?population feasibility; ?harder for low ses/ NESB; ?technical issues for 100,000+; many want to consent once only	27	16	2.8	3.4	75.0			
2.7	Registry trials	Criteria for selection, stratification	See 2.13 below	30	21	3.4	4.0	85.7	Varies	Varies	Varies

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Item #	Research Method	Feature	What would need to be done to enter/inform GenV?	Possible N	Actual N	Feasible Mean	Value Mean	% high F+V*	Exists	Kept	Centralised
2.14	Registry trials	Non-GenV trial participants join GenV at any age; prior, long term FU	GenV develops consent; trial or GenV administers; trial and GenV mutually enriched (# missing reduced for trials and GenV)	30	21	3.2	3.6	66.7			
5.2	Population Trials	Feedback to parents	Basic feedback at GenV specific waves and digital 'push' data collection; otherwise may not be possible/beneficial (as per UK Biobank RCTs)	30	17	3.3	3.4	70.6			
5.4	Population Trials	Select and recruit within GenV at later ages	May not be possible – must maintain reliable addresses/contacts at all times; shifts scoring/processing to real time; adds GenV-specific burden	30	17	3.0	3.9	64.7			
5.8	Population Trials	Consent for mother and father for administrative data to enter GenV	May need consent waiver – no current mechanism to reliably contact and consent father	30	15	3.1	4.3	73.3			
5.10	Population Trials	Consent of both GenV and population trials need to reflect relationship between GenV and other research	Consent wording by trial and GenV recognises needs of wide range of data sources – will need to be broad	30	15	3.3	3.8	80.0			
5.12	Population Trials	How can consent account for unknowns	Make consent broad; trials collect any additional specialised info/data; dynamic consent could cover this but note burden/literacy requirements	30	18	3.1	4.1	66.7			
6.8	Health services	Subtle pop-ups in GP surgery	GP incentives? Vendors to enhance software? Pop-up for all in-age children? Likely to include some non-GenV participants – problem?	29	14	1.9	3.2	35.7			
7.5	Place-based	Investigate options to collaborate with a small number of LGAs to test GenV ideas	Build partnerships, attain funding, determine how this meshes with GenV Principle of inclusivity at the state-wide level	18	9	3.3	3.9	100.0			

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Appendix 6: Survey respondent comments

Session 1 – Discovery research & biobanks

Respondents were able to provide additional comments at the end of each survey section. Across the seven sections, some respondents stated that they were unable to respond on all of the features because they did not have a clinical background and/or lacked knowledge in the area.

> *As a non-clinician, I was only able to comment on a few areas. (Discovery research & biobanks)*
>
> *I have left a lot of "Don't knows" and blanks because I really don't know the areas well enough. (Discovery research & biobanks)*
>
> *I'm unsure about what question 5 refers to (re. phenotype). (Clinical & Registry Trials)*
>
> *Unsure of what feedback to parents meant. (Population Trials)*
>
> *Not sure what this means - Consent for mother and father for administrative data to enter GenV? Needing consent from both instead of one? (Population Trials)*
>
> *I am unsure what you mean by dynamic consent. (*Discovery research & biobanks*)*

Another respondent highlighted that they were unsure of how to place value on certain items without further information due to having varied perspectives on them.

> *I'm afraid that I'm not sure of the value of a number of items without additional information. Wearing my 'hard to reach' population hat, I would consider the feasibility of a number ideas difficult and requiring creative engagement with communities. Wearing my 'translation' hat I would put priority on ideas that ensure stakeholders have buy in and have genuine participation/partnership guiding what is most important, adds value, feasible and actionable for families, service providers and policy makers. (*Discovery research & biobanks*) As a non-clinician, I was only able to comment on a few areas.*
>
> *I cannot judge on value. I can just judge on feasibility from an IT system and data management perspective.*

Some respondents also warned in Discovery and research & biobanks and Clinical & Registry Trials sections of the survey to be wary of being too ambitious with the scope of GenV without well-developed research aims and/or questions.

> *Without more specific achievable research aims in mind I think it is dangerous to make the scope too ambitious. (Discovery and research & biobanks)*
>
> *I felt slightly more comfortable on this page, but still there is huge need for the development of research questions (in particular, proposed interventions for trials) to make this more concrete. (Clinical & Registry Trials)*

One respondent indicated that they were unsure of how dynamic consent would work as the consent process for GenV.

> *I didn't rate dynamic consent because not sure what that would look like for Gen V and degree of difference from current plan. (Discovery and research & biobanks)*

It was also suggested by one respondent that the rare disorder initiative should be external to GenV.

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The rare disorder initiative should be done outside of GenV. Something that we can support but shouldn't do. Pathology blood samples are already stored but only for a year. Accessing these is common and easy for research, even if frozen (Discovery and research & biobanks)

A respondent provided some insight into the practicality of collecting cord blood and placental samples and suggested that dedicated staff could assist with the collection of samples.

Cord blood and placental samples should theoretically be easy to collect as the placenta is usually discarded following birth. However, in practice these can be very difficult to collect without dedicated staff to assist with collection protocols since the midwives caring for women are focused on the baby and the woman at the time of birth (rather than the placenta!!!!) (Discovery and research & biobanks)

It was advised by respondents in the *Discovery and research & biobanks* and *Health Services Research* survey sections that data and samples already collected and stored should be maximised.

Best value for effort would be to use the data and samples that are already collected but not collated or discarded, rather than adding additional burden in terms of consent and operation. (Discovery and research & biobanks)

Finally, it was stated by one respondent that *Amniocentesis sample omitted from list. These are more common than CVS samples now. Many cytogenetics samples go to VCGS - but not all.*

Session 2 - Clinical & Registry Trials

Some respondents during the *Clinical & Registry Trials* section of the survey highlighted the potential for GenV to engage with trials and proposed approaches to achieve this.

Why couldn't GenV identify individuals meeting trial criteria in not real time - this would be easy and useful. Eg those on an asthma preventer and a new asthma prevention treatment trial. For this value = 5 and feasibility = 4. (Clinical & Registry Trials)

Session 4 - Population health & learning

One respondent posed the question of whether or not GenV should link or accept duplications of blood spot samples from parents.

Blood spot for both parents - some duplication for babies whose parents were born in Victoria/NZ/other states that have long-term storage policies. Which raises the question of whether we should link or accept the duplication? (Population health & learning)

It was raised as a concern by one respondent that the proposed ideas and suggestions could potentially divert GenV away from key undertakings.

I am concerned that some of these suggestions are too left field, low yield and will distract from core activities and data/samples. (Population health & learning)

Another respondent stated, *Lots of good ideas here but would need massive pilot effort to determine feasibility for many of them*.

Session 6 - Health services research

After completing the *Health services research* section of the survey, some respondents raised the question of who would be best to complete the HRQOL questionnaire. One respondent suggested parents and then children/youth at an appropriate age.

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Whose perception of HRQOL - would that be of paediatrician, GP etc? Might be more straightforward to have parents complete via push mechanisms and then children/young people when old enough. (Health services research)

Whereas, another respondent suggested a GP or paediatrician should complete the HRQOL instead of in an Emergency Department (ED) or hospital setting.

ED / hospitalisation HRQL - I think this has less value than info from a GP or paed, as the GP/paed presumably have a longer standing relationship with the child/family. If they don't already have this relationship, they have more time in a new patient appointment to discuss this with the family than in an ED setting. (Health services research)

Moreover, a respondent questioned the appropriateness of the HRQOL for those with chronic health problems and/or disabilities.

Also HRQOL not great for those with chronic health problems and disabilities because some questions rely on ability to do things - which is a marker of their disability rather than QOL. (Health services research)

One suggestion was made by a respondent to have families complete HRQOL via mobile phone push notifications while ensuring it remains low burden to families.

The GenV push to mobile phone HRQL would be fantastic, and most reliable/regularly captured? Some digging to do in terms of acceptability, since GenV is meant to be low-burden. If acceptable, I think this is worth pursuing. (Health services research)

A couple of respondents also highlighted the importance of being careful with push notifications and to not over burden families with requests.

Need to be careful about what is pushed, which apps etc. as parents could become inundated with requests. The vision of wanting to influence the 'point of care' is great - but may need to be built stepwise once the evidence is available to know what we would want to influence in a prioritised way. (Health services research)

Moreover, one respondent warned, *I'd be wary of additional burden on GP or paediatricians - even if perceived as 'modest' from perspective of GenV*.

Strategies were suggested by one respondent in keeping in contact with GenV families.

To track mobile phone changes you could gain consent from the families who enter the study to ask their regular health providers (GP, paed) for their most recent contact details if the study loses contact with them. Alternatively, you could get them to nominate a family member or friend they are happy for you to contact if you lose touch (Children's Attention Project led by Emma Sciberras has used this method). Could be worth chatting to Right@home team on how they track their families (vulnerable families that switch mobile numbers & home addresses frequently). (Health services research)

Session 7 - Place-based research

After completing the place-based research section of the survey, one respondent highlighted some ideas of linking process features rather than having them separate, developing a framework and indicators as well as linking GenV data with government data.

I see the three process ideas as integrally linked rather than separate ideas. Work with partners to develop a framework and indicators for community use, bring GenV data into the system and use the Gen V network to access other government data. (Place-based research)

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The same respondent suggested testing this approach with a small number of LGAs but also highlighted a feasibility issue.

> *This could be prototyped with a small number of local governments for testing before scaling. The most significant feasibility issue is that we don't have any funding for this activity. (Place-based research)*

Another respondent suggested working with LGAs to determine a framework and indicators that GenV could incorporate.

> *There are many existing frameworks and indicators and great variability in what data is needed by communities. Unsure how easy it will be to land on a framework - this will best be investigated through work with trailblazer LGAs. (Place-based research)*

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