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

Executive Summary

(See full paper)

Authors

Sarah Davies,[1,2] Lauren Davenport,[1,2] Karen Lamb,[3] Melissa Wake,[1,2]

Affiliation

1 Murdoch Children's Research Institute, Royal Children's Hospital, Parkville, Victoria, Australia
2 Department of Paediatrics, The University of Melbourne, Parkville, Victoria, Australia
3 Melbourne School of Population and Global Health, The University of Melbourne, Parkville, Victoria, Australia

Publication date

July 2020

Series Number

2020-03

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.

Key words

Research methodology, Brainstorming sessions; Survey

Citation

Davies S, Davenport L, Lamb K, Wake M (2020). Developing GenV's Research Methodologies: Brainstorming Sessions and Survey 2018. *Generation Victoria Working Paper 2020-03. doi: 10.25374/MCRI.8234006*

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.

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 – i.e., 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 e.g. Centrelink, homelessness, child protection data
(5) Consent for mother and father for administrative data to enter GenV

doi: 10.25374/MCRI.8234006

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.

doi: 10.25374/MCRI.8234006