

GenV Parent Consultations Survey 2019

Executive Summary

(See [full paper](#))

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Abstract

To inform GenV's design, messaging and materials, we consulted over 500 current and expectant Victorian parents (members of a national data collection panel) in an online survey testing responses to information about GenV, including sections of its draft Parent/Guardian Information Statement. Most parents were supportive of GenV, with very few (< 10 per cent) negative responses. Those who felt most positive were motivated by benefits for themselves and others and by contributing to public good research. Areas of some sensitivity included data security, privacy and confidentiality, and the collection and use of biosamples. Providing information about both the benefits and perceived risks of GenV will be important to enable parents to make informed choices to take part in GenV itself.

Keywords

Parent; Child; Cohort; Consultation; Communication; Data security; Biosamples; Online survey; GenV

Citation

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Aboriginal acknowledgement

We acknowledge the Traditional Custodians of the land upon which we are situated. We pay our respect to their Elders - past, present and emerging.

Executive Summary

Background

For Generation Victoria (GenV) to be successful in its vision, it must maximise recruitment and obtain informed consent for wide-ranging data access and biosample collection. This will rely on parents and the community having a positive attitude towards GenV and a clear understanding of what GenV means for them and the public. This will be enabled both by GenV's Parent/Guardian Information Statement and, before and during recruitment of the vanguard and main cohorts, a range of platforms to build the social contract. These include publicly-accessible (e.g. social media, the press, advertising) and participant-specific materials (e.g. through antenatal services, on GenV's website). It is critical that the messaging and materials fulfil information needs, support uptake and ongoing participation, and meet ethical and legal obligations for informed consent.

A parent consultation study was therefore undertaken in late 2019 to seek feedback on proposed participant messaging and information to inform GenV's design, materials and processes. Specifically, we were interested in how current and expectant parents responded to participant information about GenV and to identify areas that were most important to parents' decision making.

Method

An Australian data collection agency, the Online Research Unit (ORU), engaged the sample for this study through their online panel of over 350,000 Australian adults. The ORU sent an invitation via email to panel members with a link to the online survey. To be eligible, participants had to be: aged 18 years or over; be a parent of a child <5 years old, or be pregnant, or have a partner who was pregnant; residing in Victoria; have internet access; and be able to read the information statement and complete the survey in English. Participants received a small remuneration via a points system with the ORU for completion of the GenV survey. Ethical approval was received prior to the survey.

The survey comprised:

- **Demographic information**
- **Contextual exploration** – participants were asked about sources of advice and guidance about child health and wellbeing, and attitudes towards health, medical and social research.
- **Message testing** – written information from GenV's draft Parent/Guardian Information Statement was presented and participants were asked to rate their feelings towards GenV. In some sections, participants were randomised to receive different information to test whether different forms of messaging or designs of GenV influenced participants' feelings about GenV.
- **Decision making** – participants were asked what areas they would like to know more about and the factors influencing their overall attitude to GenV.

Results

A total of 504 current and expectant parents completed the survey. Most were female (72 per cent), aged between 30 and 39 years (68 per cent), lived in metropolitan Melbourne (86 per cent), and had an undergraduate or postgraduate university degree (64 per cent). The most common ethnic backgrounds were Anglo-Celtic (44 per cent), Asian (28 per cent) and European (24 per cent).

Key findings were:

- The most common sources of advice and guidance about child health and wellbeing were overwhelmingly general practitioners (GPs), family and friends, and maternal and child health nurses.
- Across the information presented about GenV, around one-half to two-thirds of parents consistently felt positive about GenV, while around one-quarter to one-third felt neutral; jointly, these groupings accounted for around 95 per cent of participants.
- Very few participants reported feeling negative about GenV, and support differed little by messaging frame or design of GenV.
- There were slight decreases in positivity following information about biosamples and data security, and an increase following information about GenV being voluntary and that participants could withdraw later.
- For parents who felt positive about GenV, factors influencing decision making were the potential benefits for themselves and their child and for others like themselves and their child, followed by wanting to contribute to research for the public good. In contrast, for parents who felt negative or neutral/uncertain about GenV, the most influential factors were privacy and confidentiality, potential misuse of data and trust in the organisations involved.
- Most (80 per cent) parents reported that after reading all the information they felt very or quite confident to make a decision about participating in GenV.
- The areas parents would like to know more about in order to decide about participating in GenV were protection of privacy and confidentiality, types of data collected, and used of biological samples.

Conclusions

Overall the study demonstrated good support for GenV among expectant parents and parents of young children in Victoria. Those who felt most positive about GenV were motivated by benefits for themselves and others and by making a contribution to public good research. Areas of sensitivity were around data security, privacy and confidentiality, and the collection and use of biosamples. Providing information that addresses both the benefits and perceived risks of GenV will be important for enabling parents to make informed choices about taking part in GenV.