

# GenV Parent Consultations Survey 2019

## Authors

Elizabeth K. Hughes,<sup>1,2</sup> William Siero,<sup>1,2</sup> Simon Welsh,<sup>3</sup> Ben Edwards,<sup>4</sup> Alisha Gulenc,<sup>1</sup> Melissa Wake<sup>1,2</sup>

## Affiliation

1 Murdoch Children's Research Institute, The Royal Children's Hospital, Parkville, Victoria, Australia

2 Department of Paediatrics, The University of Melbourne, Parkville, Victoria, Australia

3 Chorus Consulting, Wodonga, Australia

4 Australian National University, Canberra, Australian Capital Territory, Australia

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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

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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.

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## List of abbreviations & glossary

Cohort 2020s	Cohort 2020s is the sample of newborns and their parents that will be recruited from across the state of Victoria Australia to participate in Generation Victoria.
FAQs	Frequently asked questions
GenV	Generation Victoria, an initiative led from the MCRI with partners across Victoria, that aims to help improve Victorians' health, development and wellbeing through the establishment of one of the world's largest birth and parent cohorts – see <a href="https://genv.org.au/">https://genv.org.au/</a>
GPs	General practitioners
HREC	Human research ethics committee
MCRI	Murdoch Children's Research Institute
NBS	Newborn bloodspot screening
ORU	Online Research Unit
Vanguard Cohort	The Vanguard Cohort is the sample to be recruited during the pilot phase of Generation Victoria. The sample will be recruited from a small number of Victorian hospitals prior to statewide recruitment.

# 1. 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.

## 2. Introduction

The primary objective of GenV is to create large, parallel whole-of-state birth and parent cohorts for discovery and interventional research. GenV will be open to all babies born in the state of Victoria over the two-year period 2021-2022 (Cohort 2020s) and blends study-collected, study-enhanced and linked data. It will be multi-purpose, supporting observational, interventional, health services and policy research within the same cohort. It is designed to address physical, mental and social issues experienced during childhood, as well as the antecedents of a wide range of diseases of ageing. It seeks to generate translatable evidence (prediction, prevention, treatments and services) to improve future wellbeing and reduce the future disease burden of all children and the adults they become.

For 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. GenV must also consider how its conduct affects the broader scientific community and ensure this is at best positive or at worst neutral. To do this, GenV must build and maintain the social contract and provide participants with appropriate materials to enable them to make an informed decision.

The social contract within science refers to the relationship between the scientific community and the general public as it relates to the scientific community's obligation to uphold socially and culturally acceptable behavioural norms, maintain trust between all parties and provide benefit to the public (1). GenV must achieve all of these if it is to meet its objectives. Science is dependent upon the social contract for its success, as it requires resources provided by the public and an appropriate degree of autonomy and self-governance granted by the public. Furthermore, GenV will ask a considerable amount of its participants in the sharing of their personal data and biosamples, which must be given due respect.

In the lead up to state-wide recruitment of Cohort 2020s and the preceding Vanguard Cohort, GenV will use a range of platforms to build the social contract. These include social media, the press, advertising and the GenV website - all of which will be accessible by the general public. We will also utilise participant-specific materials such as posters and flyers in maternity services, study brochures in antenatal information packs, GenV videos in waiting rooms, and a list of frequently asked questions (FAQs) on GenV's website. During the recruitment period, materials and information will also be made available to each individual parent to help them make an informed decision on participation. This will include the Parent/Guardian Information Statement, animated video, and information provided verbally by the GenV recruiter.

It is critical that the messaging and materials anticipate and address the questions prospective participants may have, support uptake, meet ethical and legal obligations for informed consent, support ongoing participation, and maintain the social contract. Furthermore, the messaging and materials will need to be relevant to the diverse Victorian population.

A parent consultation study was therefore undertaken 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 decision making.

## 3. Methods

### Participants and Procedure

The Online Research Unit (ORU) engaged the sample for this study. The ORU is an Australian data collection agency that maintains an online panel of over 350,000 Australian adults recruited through both online and offline methods (e.g. random-digit dialling and address-based sampling). The ORU offered the survey to potential participants on their existing panel, to be voluntarily completed if they met eligibility criteria. Note the survey was only available in English, with GenV reaching other diverse groups by alternate methodologies (see Discussion).

To be eligible for the GenV survey, the panel members had to be:

- aged 18 years or over
- a parent of a child < 5 years old, or be pregnant, or have a partner who was pregnant
- residing in Victoria
- have internet access
- be able to read the information statement and complete the survey in English.

The ORU sent an invitation via email to panel members with a link to the online survey. Invitations were targeted to panel members based on their profiles, where possible (e.g. a Victorian address). The first screen of the survey contained the Parent/Guardian Information Statement and a checklist to confirm their age, parenting status, residence in Victoria and understanding of the information statement. If confirmed as eligible, they continued on to the survey on the next screen. If not eligible, the survey ended.

The ORU remunerates its panel members for completion of surveys using a points-based system whereby members accumulate points for each survey completed. Points can be redeemed for a store gift card. Participants received \$3-\$5 in points for completion of the GenV survey.

The survey was open for completion from 23 September 2019. When the number of completed surveys reached 500 on 3 October 2019, the survey was closed to new participants. Six surveys in progress were subsequently completed, bringing the total completed surveys to 506.

The study was approved by The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC 2019.011). Consent was implied by completion of the survey.

### Measures

The survey (see Appendix 1) comprised 34 items with mostly Likert scales and some multiple choice and short free-text comment sections. The survey domains were:

- **Demographics**
- **Contextual exploration** – 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 asked to rate their feelings towards GenV<sup>1</sup>. Within several sections, participants were randomised to receive different information to test whether different forms of messaging or designs of GenV influenced participants' feelings about GenV.

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<sup>1</sup> Additional questions asked participants to rate whether they understood and believed the information. These data are not reported herein.

- **Decision making** – asked what areas participants would like to know more about and the factors influencing their overall attitude to GenV.

## 4. Results

### Demographics

A total of 506 adults living in Victoria completed the survey. As we do not know how many eligible individuals chose not to participate, the uptake rate is unknown. Two were excluded as they did not meet the inclusion criterion of being a parent or expectant parent. As shown in Table 1:

Demographics of the sample (n = 504) Table 1, of the 504 remaining, most were female (72 per cent), aged between 30 and 39 years (68 per cent) and lived in the metropolitan area of Melbourne (86 per cent). Almost all had a post-school qualification (91 per cent), with nearly two thirds (64 per cent) having an undergraduate or postgraduate university degree. The most common ethnic backgrounds were Anglo-Celtic (44 per cent), Asian (28 per cent) and European (24 per cent). All participants were parents, with most having one (40 per cent) or two children (46 per cent). Around 12 per cent were currently pregnant or had a partner who was pregnant, and 40 per cent were hoping to have a child within the next 2 years.

**Table 1:** Demographics of the sample (n = 504)

Demographic		n (%)
<b>Sex</b>	Male	143 (28)
	Female	361 (72)
<b>Age</b>	18-24 years	11 (2)
	25-29 years	51 (10)
	30-34 years	177 (35)
	35-39 years	167 (33)
	40-44 years	86 (17)
	45-50 years	8 (2)
	> 50 years	4 (1)
<b>Location</b>	Metropolitan Melbourne	435 (86)
	Other Victorian	69 (14)
<b>Secondary Education</b>	Finished Year 12	467 (93)
<b>Post-secondary Qualification</b>	Certificate, Diploma	135 (27)
	Under- or post-graduate degree	324 (64)
<b>Ethnicity<sup>a</sup></b>	Anglo-Celtic	215 (44)
	Asian	134 (28)
	European	115 (24)



Demographic		n (%)
	Middle Eastern	18 (4)
	African	8 (2)
	Pacific Islander	6 (1)
	Aboriginal or Torres Strait Islander	5 (1)
	Other <sup>b</sup>	23 (5)
	(Mixed)	34 (7)
Number of children	1	198 (40)
	2	229 (46)
	3	57 (11)
	4-7	17 (3)
Pregnant	Now (self or partner)	61 (12)
	Not now, hoping within next 2 years	200 (40)
	No now, no plans within next 2 years	243 (48)

<sup>a</sup> excluding 'prefer not to answer' (n = 16); <sup>b</sup> Included 'Australian' (n = 18) and 'New Zealander' (n = 3)

## Sources of Health Information

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 (MCH) nurses (see Table 2). Of the online resources listed, the most commonly used were the Raising Children Network and Kids Health Info. Around a third of parents also reported using Facebook parents' groups and the Nurse-On-Call phone line.

**Table 2:** Sources of advice and guidance about child health and wellbeing

	n (%)
<b>General Practitioner (GP)</b>	390 (77)
<b>Family/friends</b>	380 (75)
<b>Maternal and Child Health Nurse</b>	345 (69)
<b>Raising Children Network website</b>	205 (41)
<b>Kids Health Info</b> (Royal Children's Hospital app/website)	189 (38)
<b>Facebook parents' group(s)</b>	160 (32)
<b>Nurse-On-Call phone line</b>	158 (31)
<b>BabyCentre website</b>	124 (25)
<b>Local parents' group</b>	115 (23)
<b>Better Health Channel app/website</b>	99 (20)

Other	7 (1)
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## Attitudes to Health Research

Although the sample were members of an online research panel, just 17 per cent reported having previously participated in health, medical or social research (not including market research; see Table 3). Only 5 per cent felt negatively about their child being part of health or social research led by a not-for-profit research institute, although a substantial portion (42 per cent) felt neutral about this prospect.

**Table 3:** Attitudes towards health, medical and social research

		n (%)
<b>Previously participated <sup>a</sup></b>	Yes	87 (17)
	No	387 (77)
	Can't say	30 (6)
<b>Child's future participation <sup>b</sup></b>	Very positive or Positive	266 (53)
	Neutral	212 (42)
	Negative or Very negative	26 (5)

<sup>a</sup> Have you taken part in health, medical or social research (other than market research) before?

<sup>b</sup> In general, how would you feel about your child being in a health/social research project led from a not-for-profit research institute?

## Message Testing: Introduction to GenV

Table 4 shows how parents responded to four sets of introductory messaging about GenV.

Across all of this information, very few parents reported negative feelings towards GenV (0.4-4 per cent).

After reading the first short introductory statement about the need for GenV, most families felt positive about GenV (71 per cent) and very few felt negative (0.8 per cent). There was no significant difference between participants randomised to one of two forms of messaging: one beginning with a positive messaging frame ("Most Australian children and parents can look forward to a healthy and happy future..."), and another beginning with a negative messaging frame ("Families today are confronted by increasing rates of complex health and development problems...").

For the subsequent three sets of introductory information, participants were asked if the information had *changed* their feelings about GenV. Following a description of what GenV is, most felt either more positive (56 per cent) or the same (43 per cent) about GenV. There was no significant difference in responses between participants randomised to receive a description of GenV as a "learning cycle" and those randomised to receive a description of GenV as creating "building blocks" for future research.

In the next set, all participants received the same information about why they should take part in GenV (e.g. to help “create a healthier future for all children and parents”). Again, most parents felt either more positive (52 per cent) or the same (46 per cent) about GenV.

In the final introductory set, participants were randomly assigned one of three case studies describing how GenV could benefit the community. Most (63 per cent) of participants felt more positive about GenV and 35 per cent reporting no change. There was a significant difference in responses to the three case studies,  $\chi^2(1,4) = 12.1, p = .02$ . Specifically, 70 per cent, 64 per cent and 56 per cent respectively felt more positive about GenV after reading how it might improve diagnosis of food allergies, prevention of obesity, or treatment of mental illness. Negative impact of reading these case studies was minimal (highest for the case study describing prevention of obesity,  $n = 6$ , 4 per cent).

**Table 4:** Responses to introductory messaging about GenV

	Randomised Messaging Groups	Positive (%)	Neutral/ Uncertain (%)	Negative (%)	p-value
<b>Introduction to GenV</b>	Positive opening	71	29	0.4	.6
	Negative opening	71	28	1	
	<b>Total (n = 504)</b>	71	28	0.8	
		<b>More Positive</b>	<b>No real change</b>	<b>More Negative</b>	
<b>What is GenV? (randomised)</b>	Learning cycle	55	43	2	.3
	Building blocks	57	42	0.8	
	<b>Total (n = 504)</b>	56	43	2	
<b>Why should I take part in GenV?</b>	<b>Total (n = 504)</b>	52	46	1	NA
<b>Case Studies (randomised)</b>	Treatment (mental health)	56	43	1	.02
	Diagnosis (food allergy)	70	30	0.6	
	Prevention (obesity)	64	33	4	
	<b>Total (n = 504)</b>	63	35	2	

## Message Testing: What GenV Involves for Participants

Next, participants were presented with 10 short pieces of information about GenV and, after each, were asked to indicate if they felt positive about it. For several sections, participants were randomly assigned to receive different information. Table 5 shows the results.

1. **Recruitment visit:** This described the visit being shortly after birth, usually in the hospital and taking around 15-20 minutes. Most parents felt positive (66 per cent) about this and very few felt negative (5 per cent).
2. **Data linkage:** This described that GenV would “bring together information that already exists” and the types of datasets included. Most parents felt positive (62 per cent) about this and few

felt negative (6 per cent). There was no significant difference when social or justice datasets were included or excluded, or when data linkage was described as being for both the parent and child or the child only; however, the lowest positivity was reported when social or justice datasets were included *and* data linkage was for the child only (53 per cent).

3. **Biosamples:** This described that GenV would “bring together samples already collected” and the types of samples included. Over half of parents felt positive (56 per cent) about this, with 9 per cent feeling negative. There was no significant difference when routine samples were included or excluded, or when routine samples were included for both the parent and child, the parent only or the child only; however, the lowest positivity was reported when routine samples were included but for the child only (51 per cent).
4. **Future contact:** This described that GenV would “make brief contact with you from time to time to follow your and your child’s health, development and wellbeing” and included the types of contact that would be made. Most parents felt positive (59 per cent) about this and few felt negative (8 per cent). There was no significant difference when contacts included or excluded measurements and invitations into other studies; however, the lowest positivity was reported when invitations to other studies were excluded (55 per cent).
5. **Other services:** This described how GenV would “tell services that you and your child are in GenV” so they could help with short surveys or assessments during normal visits or help GenV keep contact details up to date. Most parents felt positive (62 per cent) about this and few felt negative (6 per cent). Only one version of this section was given to all participants.
6. **Consent and options:** This described what would happen once they agreed to take part (i.e. answer a few questions and provide their contact details) and the optional consents they could select (i.e. a saliva sample using a “cheek swab” and genetic testing of samples including the cheek swab). Most parents felt positive (58 per cent) about this with around 9 per cent feeling negative. There was no significant difference when optional consents included or excluded the cheek swab and/or genetic testing; however, the lowest positivity was reported when both were included (52 per cent).
7. **Feedback:** This described how GenV may provide on-the-spot feedback and general research findings but will not provide results on individual participants’ health problems. Most parents felt positive (60 per cent) about this and few felt negative (6 per cent). Only one version of this section was given to all participants.
8. **Voluntary:** This described GenV as voluntary and how they could withdraw later. Most parents felt positive (70 per cent) about this and few felt negative (5 per cent). Positive ratings were somewhat higher when participants were told they could join later if they did not consent now, but the difference was not significant (could join later = 73 per cent vs could not = 66 per cent).
9. **Data security:** This described how GenV stores and protects data and how privacy is protected if there is a security breach. Most parents felt positive (55 per cent) about this with around 10 per cent feeling negative. Only one version of this section was given to all participants.
10. **Data use:** This described the kinds of research GenV data can support and how data users are approved. Most parents felt positive (60 per cent) about this and few felt negative (6 per cent). There was no significant difference when companies were included or excluded as potential data users.

**Table 5:** Responses to messaging about what GenV involves for participants

Randomised Messaging		I feel positive about it..., (%)			p-value
		Agree	Neutral/ Mixed	Disagree	
<b>1. Recruitment Visit</b>	<b>Total (n = 504)</b>	66	29	5	NA
<b>2. Data Linkage</b>	Datasets exclude social and justice. Linkage for parent and child.	62	32	6	
	Datasets include social and justice. Linkage for parent and child.	65	29	6	
	Datasets exclude social and justice. Linkage for child only.	68	27	6	
	Datasets include social and justice. Linkage for child only.	53	40	7	.4
	<b>Total (n = 504)</b>	62	32	6	
<b>3. Biosamples</b>	Includes 10 week test, NBS and routine samples for parent and child	54	38	8	
	Includes 10 week test and NBS for parent and child	59	31	10	
	Includes 10 week test, NBS and routine samples for parent	60	30	10	
	Includes 10 week test, NBS and routine samples for child	51	42	7	.5
	<b>Total (n = 504)</b>	56	35	9	
<b>4. Future contact</b>	Includes surveys, measures, news, invites and face-to-face assessment	57	36	7	
	Includes surveys, news and face-to-face assessment (no measurements or invites)	62	34	5	
	Includes surveys, news, invites and face-to-face assessment (no measurements)	62	29	9	
	Includes surveys, measures, news and face-to-face assessment (no invites)	55	34	10	.6
	<b>Total (n = 504)</b>	59	33	8	
<b>5. Other services</b>	<b>Total (n = 504)</b>	62	32	6	NA
<b>6. Consent and options</b>	Questions, contact details, cheek swab and genetic testing	52	38	11	
	Questions, contact details, and cheek swab (no genetic testing)	54	35	11	
	Questions, contact details and genetic testing (no cheek swab)	63	30	7	

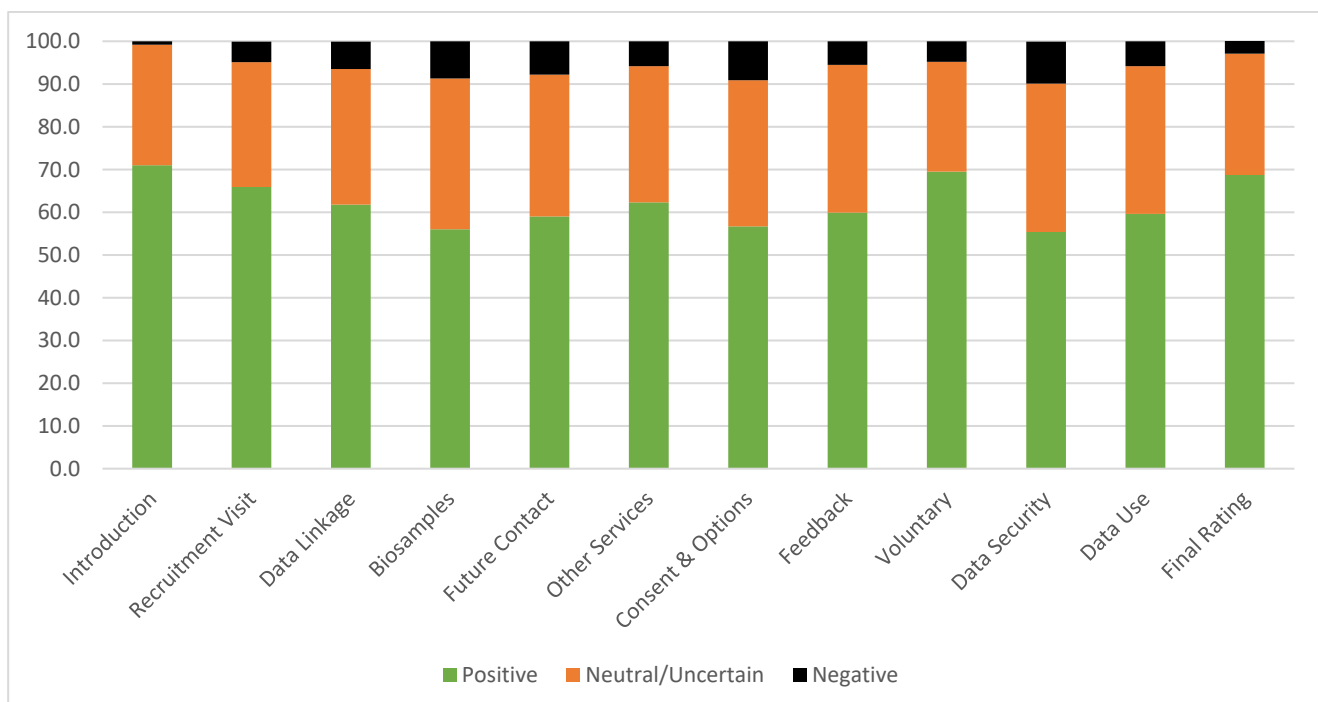
Randomised Messaging		I feel positive about it..., (%)			p-value
		Agree	Neutral/ Mixed	Disagree	
	Questions and contact details (no cheek swab or genetic testing)	58	34	8	.6
	<b>Total (n = 504)</b>	57	34	9	
<b>7. Feedback</b>	<b>Total (n = 504)</b>	60	35	6	NA
<b>8. Voluntary</b>	Includes joining later	73	23	4	.2
	Excludes joining later	66	29	5	
	<b>Total (n = 504)</b>	70	26	5	
<b>9. Data security</b>	<b>Total (n = 504)</b>	55	35	10	NA
<b>10. Data use</b>	Data users includes companies	56	37	7	.2
	Data users excludes companies	63	32	5	
	<b>Total (n = 504)</b>	60	35	6	

Note. NBS = Newborn bloodspot screening.

## Message Testing: Overall Impression of GenV

**Figure 1** Ratings of feelings toward GenV following each section of information

Figure 1 shows feelings towards GenV as rated by participants after each section of information was provided. The figure highlights that the lowest levels of positivity followed information about biosamples and data security, and highest levels of positivity followed information about GenV being voluntary and that participants could withdraw later. When asked to give a final rating of how they felt about GenV after everything they had read, 69 per cent of participants felt positive, 28 per cent felt neutral or uncertain, and just 3 per cent felt negative.



**Figure 1** Ratings of feelings toward GenV following each section of information

Table 6 shows the change in positivity from participants' initial rating to their final rating. As indicated, most participants' feelings remained unchanged (78.4 per cent). Of note, only 2.2 per cent of participants who initially felt positive or neutral/uncertain reported feeling negative after reading the information, while 8.2 per cent of participants who initially felt negative or neutral/uncertain about GenV subsequently felt positive after reading the information.

**Table 6:** Comparison of initial and final ratings of feelings towards GenV, after reading all information

		Final Rating (%)			
		Positive	Neutral/Uncertain	Negative	Total
Initial Rating	Positive	60	11	0.2	71
	Neutral/Uncertain	8	18	2	28
	Negative	0.2	0.2	0.4	0.8
	Total	69	28	3	100

## Decision Making: Influencing Factors

Participants were asked to select up to three factors influencing their attitude towards GenV. Results were compared based on the final rating of feelings toward GenV (see Table 7). There were no differences by demographic factors (data not presented).

For participants who felt positive about GenV, the top ranked factors were the potential benefits of GenV 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 participants who felt negative or neutral/uncertain about GenV, protection of privacy and confidentiality, potential misuse of data and trust in the organisations involved were the most highly ranked.

**Table 7:** Factors influencing attitudes towards GenV for total sample and by final rating

	Positive (n = 346), %	Neutral/Uncertain (n= 143), %	Negative (n= 15), %	Total (n =504), %
Potential benefits of GenV for me and my child	49	18	0	39
Potential benefits of GenV for others like me and my child	50	13	7	38
Wanting to contribute to research for the public good	46	14	20	36
Protection of privacy and confidentiality	31	45	67	36

	<b>Positive</b> (n = 346), %	<b>Neutral/Uncertain</b> (n= 143), %	<b>Negative</b> (n= 15), %	<b>Total</b> (n =504), %
<b>Trust in the organisations involved</b>	26	32	40	28
<b>Potential misuse of data</b>	17	49	60	27
<b>Time and effort involved for participants</b>	24	30	33	26
<b>Use of biological or genetic samples</b>	19	29	33	22
<b>Risks versus benefits</b>	15	31	27	20
<b>Other</b>	1	1	0	1

## Decision Making: Information Needs

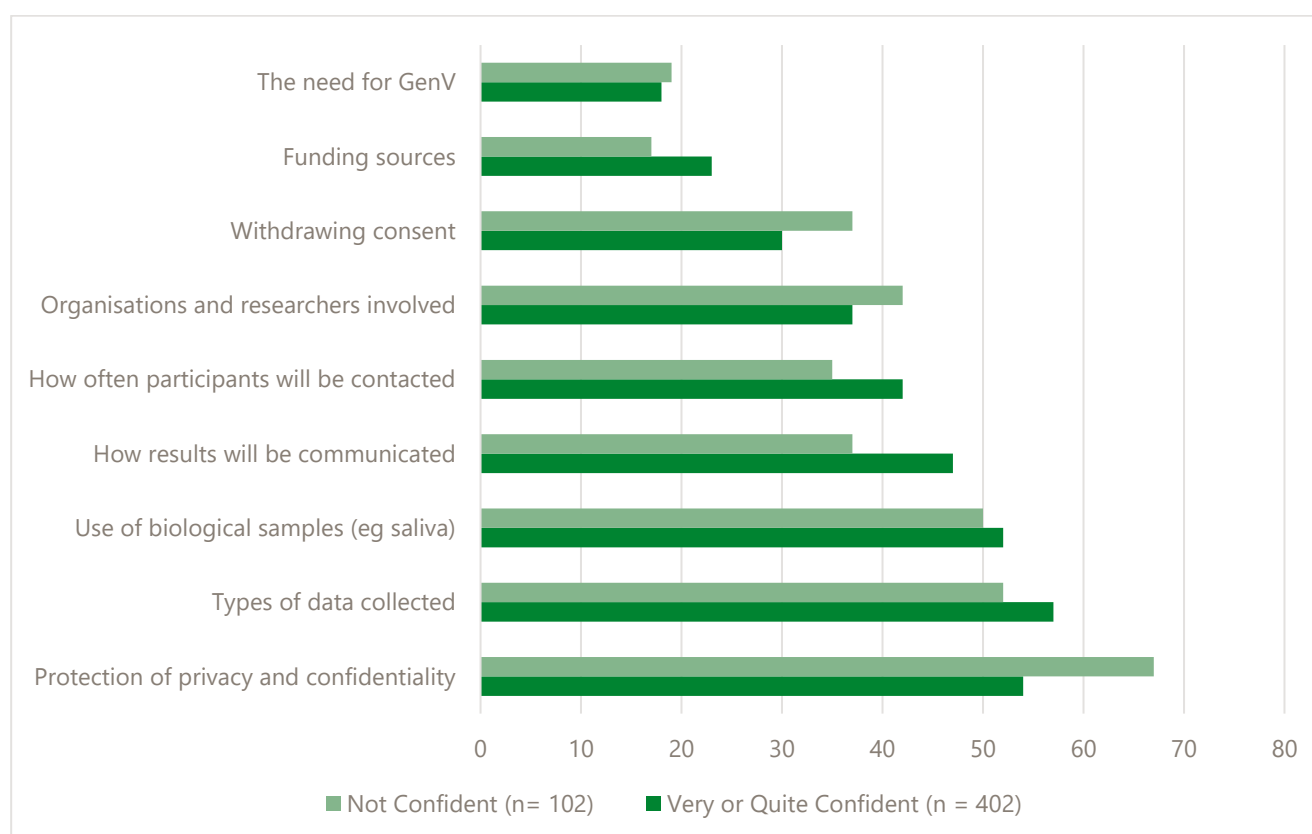
Most (80 per cent) participants reported that after reading all the information they felt very or quite confident making a decision about participating in GenV (n = 402). Participants were asked to select up to five areas they would like to know more about in order to decide about participating. As shown in Table 8, the top ranked areas of interest were protection of privacy and confidentiality (57 per cent), types of data collected (56 per cent), and used of biological samples (51 per cent). Results were compared based on participants' confidence in making a decision (see Table 8 and Figure 2). The top three factors did not differ by decision-making confidence, aside from the first and second ranked factors being reversed between the groups. Among the lower-ranked factors, those who were not confident about making a decision ranked learning more about the organisations and researchers involved and withdrawing consent more highly than those who felt confident making a decision.

**Table 8:** Percentage of parents wanting more information in each area in order to decide about participating, for total sample and by confidence in making a decision

	<b>Very or Quite Confident</b> (n = 402), %	<b>Not Confident</b> (n= 102), %	<b>Total</b> (n =504), %
<b>Protection of privacy and confidentiality</b>	54	67	57
<b>Types of data collected</b>	57	52	56
<b>Use of biological samples (e.g. saliva)</b>	52	50	51
<b>How results will be communicated</b>	47	37	45
<b>How often participants will be contacted</b>	42	35	40
<b>Organisations and researchers involved</b>	37	42	38
<b>Withdrawing consent</b>	30	37	31
<b>Funding sources</b>	23	17	22
<b>The need for GenV</b>	18	19	18



Other	1	1	1
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**Figure 2:** Percentage of parents wanting more information in each area in order to decide about participating, by confidence in making a decision

## 5. Discussion

Overall participants were very supportive of GenV and this did not change substantially as they received more information via a draft version of the proposed Parent/Guardian Information Statement. Very few parents reported feeling negative about GenV, and support differed little by messaging frame or design of GenV. 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.

Participants reported that GPs and maternal and child health nurses were among the most important sources of information about child health and wellbeing. Maternal and child health nurses may have been particularly influential in this sample, all of whom were already parents (whereas around half of GenV participants will be first-time parents). Nonetheless, this highlights the need to ensure these professional groups are aware of and supportive of GenV as they have a strong influence on parents' decision making and, in turn, could be detractors of GenV if uninformed, misinformed or unsupportive. Friends and family were rated almost equal to GPs as important sources of information, pointing to a need for the GenV social awareness campaign to reach well beyond expectant parents and professional groups.

The highest support for GenV (99 per cent positive or neutral) was reached after the introductory

messaging. This suggests that, even with very minimal information, parents are supportive of GenV and its aims. Support varied little by how the messaging was framed, other than for the case studies in which a case describing improved diagnosis of food allergies was the best received. Possible reasons (other than chance) are that food allergy is common, concerning for parents of very young children, and perhaps less stigmatised than the conditions in the other examples (mental illness and obesity).

More detailed information about what GenV involved did not lessen parent support but did identify some areas of sensitivity. Positive feelings towards GenV decreased (though only slightly) when information described data security, biosamples and genetic testing - areas are known to be of particular concern to the public (2, 3). Potential misuse of data and protection of privacy and confidentiality were the factors rated as most influential for parents who felt negative or neutral about GenV. Privacy, the types of data collected and the use of biological samples were also the areas parents most wanted to know more about to help them make a decision about GenV. There appeared to be some minor variations in support when parents were presented with information including or excluding different datasets or samples; however, none were significant. Even so, it will be important that GenV provides accessible and clear information about these topics, for example through FAQs, phone infoline, and the website.

Encouragingly, very few parents who initially felt positive or neutral about GenV reported feeling negative after reading the detailed information about GenV, and a good portion of those who initially felt negative or neutral about GenV subsequently felt positive. It should be noted that the information was provided without any prior context. It is possible that, with a team member on hand to answer questions and explain aspects in more detail, greater understanding and support can be fostered.

It is also important to consider what motivates parents to participate. In this study, parents who felt positive about GenV were motivated by the potential benefits to themselves and their child, benefits to others like them and their child, and the desire to contribute to public good research. This information should therefore stay at the forefront when conveying what GenV is and what it aims to achieve, both at recruitment and for sustaining engagement of participants in GenV into the future.

The strengths of the study include the large sample size and representation of age, ethnicity and family size. Sample limitations included lower representation of parents from regional and remote areas, the requirement to be able to read English, and the high education level of the sample [91 per cent had a post-school qualification compared to 68 per cent of Australians aged 20-64 years (4)]. GenV is consulting more broadly, via a range of methods including focus groups and community consultation, with potential participant groups not well represented in this study. This includes non-English speaking, low literacy, and various cultural groups (e.g. Aboriginal and Torres Strait Islander communities).

While all participants were parents of young children and some were pregnant, none were expecting their first child. GenV will include many first-time parents, who may respond to GenV in different ways to those who already have children. The over-representation of females may not be of great concern, as it aligns with GenV's recruitment approach in birthing hospitals, with mothers likely to be the first point of contact and the one to provide consent for their child's participation.

Online market research panels may bring their own attitudinal biases, for example being more receptive to participating in research. Here, however, very few participants (17 per cent) reported previous participation in health, medical or social research (excluding market research). Finally, surveys can have poor predictive validity. Parents may report that they would be happy to participate in a project if invited, but the ultimate uptake can be very different. According to revealed preference theory (5), "It is not what you say, it is what you do that reveals what you want.". Thus, the true uptake of GenV will only be known once parents have the opportunity to join.

## 6. Conclusion

Victorian parents surveyed in the study were very supportive of GenV. The findings indicated that providing information that addresses both the benefits and perceived risks of GenV will be important to enable parents to make informed choices to take part in GenV itself.

## 7. Author Acknowledgements

We would like to thank the parents who participated in this study, the GenV staff and investigators who provided input and facilitated the study, and the ORU for their assistance with data collection.

## 8. References

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## 9. Appendix 1. Parent Consultation Survey

This study is being run by the Murdoch Children's Research Institute (MCRI) in Melbourne.

The survey briefly explores attitudes on health and social research and trends. It then introduces Generation Victoria (GenV), a new study being planned from the MCRI. It tells you about GenV, then asks for your feedback on the information given. Your feedback will help us shape how we communicate GenV to parents, and to prepare answers to questions we may not have thought of.

The survey takes 25 minutes to complete.

Your views will remain completely confidential. We will only use the information you provide for research purposes.

If you would like to know more about this study, please contact us at [genv@mcri.edu.au](mailto:genv@mcri.edu.au)

You can withdraw from this study once you've started the survey – just close the browser before you get to the end. By choosing to submit your responses to the survey, you are agreeing to take part in this project.

Please answer the following questions before continuing:

- 1) Are you: (a) a parent of a child aged under 5 years old, OR (b) pregnant, OR (c) have a partner who is pregnant? ☐ Yes ☐ No
- 2) Are you currently living in Victoria, Australia? ☐ Yes ☐ No
- 3) Have you read and understood the information above? ☐ Yes ☐ No

### SECTION 1 – ABOUT YOU

#### 1) What is your age group?

- ☐ Under 18 [*terminate*]
- ☐ 18-24 years
- ☐ 25-29 years
- ☐ 30-34 years
- ☐ 35-39 years
- ☐ 40-44 years
- ☐ 45-49 years
- ☐ 50 years or over

#### 2) What is your gender?

- ☐ Male
- ☐ Female
- ☐ Other

#### 3) How many children do you currently have? [*numeric*]

#### 4) Are you planning or hoping to have a child within the next two years?

- ☐ I'm pregnant now
- ☐ My partner is pregnant now
- ☐ I/we aren't pregnant - not hoping for a child in the next two years
- ☐ I/we aren't pregnant - hoping for a child in the next two years

**5) What is your postcode?**

[4 digits]

**6) What level of school did you complete?**

- ☐ Year 10 or less
- ☐ Year 11
- ☐ Year 12 or equivalent (finished school)

**7) What are your post-school qualifications?**

- ☐ Trade/Apprenticeship
- ☐ Certificate, Diploma
- ☐ Undergraduate university degree (eg Bachelors, Honours)
- ☐ Postgraduate university degree (eg Masters, doctorate)
- ☐ None
- ☐ Other (describe) [text]

**8) Which of the following best describes your background? (Tick all that apply)**

- ☐ Aboriginal and/or Torres Strait Islander
- ☐ Anglo-Celtic (e.g. British, Scottish, English, Irish)
- ☐ European – Southern (e.g. Greek, Italian)
- ☐ European – Northern/Western/Eastern (e.g. French, Polish, Swedish)
- ☐ East Asian (e.g. Chinese, Korean, Japanese)
- ☐ Southeast Asian (e.g. Vietnamese, Thai, Filipino)
- ☐ South Asian (e.g. Indian, Pakistani, Bangladeshi, Nepali)
- ☐ Middle Eastern (e.g. Lebanese, Iraqi, Turkish)
- ☐ Pacific Islander (e.g. Fijian, Samoan)
- ☐ Northern African (e.g. Egyptian, Sudanese, Moroccan)
- ☐ Southern African (e.g. Zimbabwean, South African)
- ☐ Other, please specify....
- ☐ Prefer not to answer

## SECTION 2 – HEALTH INFORMATION AND RESEARCH

**9) Which of the following sources do you use for advice and guidance about child health and wellbeing? (Tick all that apply)**

- ☐ Family/friends
- ☐ Local parents' group
- ☐ Facebook parents' group(s)
- ☐ Raising Children Network website
- ☐ Kids Health Info (Royal Children's Hospital app/website)
- ☐ Better Health Channel app/website
- ☐ BabyCentre website
- ☐ Nurse-On-Call phone line
- ☐ Maternal and Child Health Nurse
- ☐ General Practitioner (GP)
- ☐ Other, please specify: [text]

**10) Have you taken part in health, medical or social research (other than market research) before?**

- ☐ No
- ☐ Yes
- ☐ Don't know /can't say

**11) In general, how would you feel about *your child* being in a health/social research project led from a not-for-profit research institute?**

- ☐ Very positive
- ☐ Positive
- ☐ Neutral
- ☐ Negative
- ☐ Very negative

## SECTION 3 - INTRODUCING GENV

The following is some introductory information about a new research initiative called Generation Victoria (GenV). We are interested in your feedback, so please read carefully.

<b>Randomised (1:1)</b>	
<b>Group A (Negative Opening)</b>	<b>Group B (Positive Opening)</b>
<p><b>The Need for GenV</b></p> <p>Families today are confronted by increasing rates of complex health and development problems, such as mental illness, obesity, autism, learning difficulties, allergies and more.</p> <p>Children born today face the prospect of having a lower life expectancy than their parents.</p> <p>To help families enjoy their best lives possible, we need to get better at solving problems in health and wellbeing.</p> <p>A new research initiative, GenV, is designed to do just this.</p> <p>Led from the Murdoch Children's Research Institute and the Royal Children's Hospital, GenV will allow us to predict, prevent and treat problems with greater speed and precision than is possible today.</p>	<p><b>The Need for GenV</b></p> <p>Most Australian children and parents can look forward to a healthy and happy future. All the same, many families face complex health and development problems. These include obesity, allergies, mental illness and more.</p> <p>To help families enjoy their best lives possible, we need to get better at solving problems like these.</p> <p>A new research initiative, GenV, is designed to do just this.</p> <p>Led from the Murdoch Children's Research Institute and the Royal Children's Hospital, GenV will allow us to predict, prevent and treat problems with greater speed and precision than is possible today.</p>

**12) To what extent do you agree with the following statements about the information above:**

	Strongly agree	Agree	Neutral/ Mixed	Disagree	Disagree	Don't know/ Can't say
<b>I understand it</b>	Y	Y	Y	Y	Y	Y
<b>I find it interesting</b>	Y	Y	Y	Y	Y	Y
<b>I find it believable</b>	Y	Y	Y	Y	Y	Y

### 13) Based on this section, how do you feel about GenV?

- ☐ Very positive
- ☐ Positive
- ☐ Neutral or Uncertain
- ☐ Negative
- ☐ Very negative

## SECTION 4 –WHAT IS GENV?

<b>Randomised (1:1)</b>	
<b>Group A (Learning)</b>	<b>Group B (Building Blocks)</b>
<p><b>What is GenV?</b></p> <p>As children develop, they need feedback from the world around them to help them learn.</p> <p>To improve health and wellbeing we must also continually understand what's happening in the community, test solutions and learn from the results.</p> <p>GenV is a system to enhance this learning cycle.</p> <p><i>GenV allows us learn more deeply.</i></p> <p>It provides a complete picture of what's happening in health and wellbeing across the community. To do this, from 2021 to 2022, we would approach all parents of newborns in Victoria about taking part in GenV. With consent, we would then collect a range of health and development data and samples from parents and their babies, starting soon after birth and continuing across the course of their lives.</p> <p><i>GenV allows us to learn faster.</i></p> <p>The GenV data is paired with new research approaches and technologies to speed up discovery.</p> <p><i>GenV allows us to share the knowledge created.</i></p> <p>GenV will create new partnerships among those working for the community to improve health and wellbeing. Researchers, hospitals, practitioners and policy-makers would come together to use GenV's data to answer the important questions. GenV would also share knowledge back to parents and children about how we can manage health and wellbeing for the future.</p>	<p><b>What is GenV?</b></p> <p>GenV is building the foundations for solving health and wellbeing problems in smarter and faster ways. It asks very little effort from families.</p> <p>It will establish the building blocks for future research. These include:</p> <ul style="list-style-type: none"> <li><i>Data that give a whole picture of health and wellbeing across the community.</i> In 2021 and 2022, we are approaching parents of all newborns in Victoria about taking part in GenV. With consent, we collect data and samples from parents and their babies. We combine information about health, development, environment, services and culture. This paints a picture of how children grow and develop, how people age, and how health changes across generations.</li> <li><i>New research approaches and technologies to speed up discovery.</i></li> <li><i>New partnerships to improve health and wellbeing.</i> Researchers, communities and policy-makers can use GenV's data to answer important questions together.</li> <li><i>Ways to share knowledge back to parents and children about how best to manage health and wellbeing for the future.</i></li> </ul>

### 14) To what extent do you agree with the following statements about the information above:

	Strongly agree	Agree	Neutral/ Mixed	Disagree	Disagree	Don't know/ Can't say
<b>I understand it</b>	Y	Y	Y	Y	Y	Y
<b>I find it interesting</b>	Y	Y	Y	Y	Y	Y
<b>I find it believable</b>	Y	Y	Y	Y	Y	Y

**15) How has this information changed your feelings about GenV?**

- ☐ A lot more positive
- ☐ A bit more positive
- ☐ No real change
- ☐ A bit more negative
- ☐ A lot more negative

<b>Non-randomised</b>
<b>Why should I take part in GenV?</b>
By taking part in GenV, you are helping create a healthier future for all children and parents.
GenV aims to build a “big picture” of health and wellbeing for Victoria.
It involves a whole generation of families - from all walks of life, all ethnic backgrounds, all lifestyles, and all levels of health and disability. If you are in GenV, then its results are more likely to help people like you in the future.
During the 2-year GenV window, every baby born in Victoria can take part. We hope over 100,000 parents like you will choose to do so.
Every person matters for GenV. The more complete our picture, the more it will help to understand, prevent and treat problems for each and every child and adult.

**16) To what extent do you agree with the following statements about the information above:**

	Strongly agree	Agree	Neutral/ Mixed	Disagree	Disagree	Don't know/ Can't say
<b>I understand it</b>	Y	Y	Y	Y	Y	Y
<b>I find it interesting</b>	Y	Y	Y	Y	Y	Y
<b>I find it believable</b>	Y	Y	Y	Y	Y	Y

**17) How has this information changed your feelings about GenV?**

- ☐ A lot more positive
- ☐ A bit more positive
- ☐ No real change
- ☐ A bit more negative
- ☐ A lot more negative

## SECTION 5 – HOW GENV WORKS

GenV will bring together data from a large and diverse group of Victorian children and parents to solve health and wellbeing problems in ways that benefit the whole community. We have developed some short case examples to help tell that story.

We are interested in your feedback, so please read carefully.



<b>Each participant allocated ONE case study (on random basis)</b>		
<b>Case Study 1</b>	<b>Case Study 2</b>	<b>Case Study 3</b>
<b>This example explains how GenV might improve access to services</b>	<b>This example explains how GenV might improve diagnosis</b>	<b>This example explains how GenV might improve prevention and treatment</b>
<p>Melanie gave birth to her daughter, Jill, at a local hospital. A couple of days later, she and her partner, Peter, were approached by a GenV researcher and agreed to take part.</p> <p>The family lived in an outer Melbourne suburb, where Jill grew up a healthy and happy little girl.</p> <p>As Jill entered her later years of high school, she became withdrawn and depressed. Melanie and Peter looked for support for Jill but there seemed to be a shortage of affordable mental health services in the area.</p> <p>Researchers using GenV data were looking at mental health around the state. While they couldn't see anything about Jill personally, researchers could see there was a spike in depression among young people in the outer suburbs like where Jill lived. They could also see that the mental health services in those suburbs would not be able to meet demand for much longer.</p> <p>Working with policy-makers in government, the researchers were able to use the GenV data to make the case for increasing services in the outer suburbs. This led to new public mental health clinics opening in these areas, with young people like Jill among those to benefit.</p>	<p>Sarah gave birth to her daughter, Kate, at a local hospital. A couple of days later, she and her partner, Andrew, were approached by a GenV researcher and agreed to take part.</p> <p>When she was four, Kate became ill. She was tired more than usual, was not eating or sleeping properly, and often felt sick in the stomach.</p> <p>Sarah and Andrew were beside themselves. They visited many specialists where Kate had many tests and tried lots of different treatments. After months of searching for an answer, Kate was found to have a complex food allergy that needed a special diet.</p> <p>Researchers using GenV data had been looking at links between food allergies and a broad range of health data. While they couldn't see anything about Kate personally, researchers saw a number of children with a similar pattern of symptoms to Kate.</p> <p>They shared this knowledge among doctors and scientists – ultimately leading to the discovery of a simple test for a range of food allergies.</p> <p>Once the test was made available, other families were saved the experience of having a sick child with no diagnosis quickly available.</p>	<p>Joanne gave birth to her daughter, Alice, at a local hospital. A couple of days later, she and her partner, Adam, were approached by a GenV researcher and agreed to take part.</p> <p>From a young age, Alice was heavier than other children her age. The family's GP encouraged Alice's parents to focus on good eating habits and increasing Alice's physical activity, but despite their efforts Alice's weight continued to go up. Joanne and Adam worried about Alice's future health but were lost about how to help her.</p> <p>GenV captured data about Alice and the hundreds of children with obesity across the state. Researchers began to explore the causes of obesity using this data. They found clear patterns – not just in genetics but also in things like access to safe, local playgrounds and nutrition education in schools.</p> <p>This helped experts develop new preventative and treatment programs, including making the case for funding for new kinds of recreation facilities in areas where GenV data showed child obesity rates were high.</p> <p>Over time, researchers could see a decline in the number of children affected by obesity as the new prevention and treatment programs were taken up across the state.</p>

**18) To what extent do you agree with the following statements about the information above:**

	Strongly agree	Agree	Neutral/ Mixed	Disagree	Disagree	Don't know/ Can't say
<b>I understand it</b>	Y	Y	Y	Y	Y	Y
<b>I find it interesting</b>	Y	Y	Y	Y	Y	Y
<b>I find it believable</b>	Y	Y	Y	Y	Y	Y

**19) How has this information changed your feelings about GenV?**

- ☐ A lot more positive
- ☐ A bit more positive
- ☐ No real change
- ☐ A bit more negative
- ☐ A lot more negative

## SECTION 6 – WHAT GENV INVOLVES FOR PARTICIPANTS

This section explains the 6 main parts of GenV for participants. At this stage, we are interested in whether the information provided is easy to understand, and how you feel about some of the points raised.

**Introduction to GenV:**

A member of the GenV team visits or contacts you soon after your baby is born - usually in the hospital. GenV aims to make things as easy as possible for people who join. The visit takes around 15-20 minutes. We explain the project, and ask if you are willing to take part with your baby. If possible, we also invite your baby's other parent.

**20) To what extent do you agree with the following statements about the information above:**

	Strongly agree	Agree	Neutral/ Mixed	Disagree	Disagree	Don't know/ Can't say
<b>I understand it</b>	Y	Y	Y	Y	Y	Y
<b>I feel positive about it</b>	Y	Y	Y	Y	Y	Y

<b>Randomised (1:1:1:1)</b>	
<b>Group A (Limited linkage)</b>	<b>Group B (Broad linkage)</b>
<p><b>Part 1 of GenV:</b> Bring together information that already exists. These include:</p> <ul style="list-style-type: none"> <li>Information that services already collect for you and your child, from before your baby was born and in the future. This includes information from your and your child's health, mental health, and education records and services. With your permission, GenV can access this from government departments, from schools and kindergartens, and from hospitals, doctors and other providers.</li> <li>Information related to your neighbourhood and where you spend your time, like air pollution and childcare services near your home.</li> </ul>	<p><b>Part 1 of GenV:</b> Bring together information that already exists. These include:</p> <ul style="list-style-type: none"> <li>Information that services already collect for you and your child, from before your baby was born and in the future. This includes information from your and your child's health, mental health, education, social and justice records and services. With your permission, GenV can access this from government departments, from schools and kindergartens, and from hospitals, doctors and other providers.</li> <li>Information related to your neighbourhood and where you spend your time, like air pollution and childcare services near your home.</li> </ul>
<b>Group C (Limited linkage child only)</b>	<b>Group D (Broad linkage child only)</b>
<p><b>Part 1 of GenV:</b> Bring together information that already exist. These include:</p> <ul style="list-style-type: none"> <li>Information that services already collect for your child, from before your baby was born and in the future. This includes information from your child's health, mental health, and education records and services. With your permission, GenV can access this from government departments, from schools and kindergartens, and from hospitals, doctors and other providers.</li> <li>Information related to your neighbourhood and where your child spends their time, like air pollution and childcare services near your home.</li> </ul>	<p><b>Part 1 of GenV:</b> Bring together information that already exist. These include:</p> <ul style="list-style-type: none"> <li>Information that services already collect for your child, from before your baby was born and in the future. This includes information from your child's health, mental health, education, social and justice records and services. With your permission, GenV can access this from government departments, from schools and kindergartens, and from hospitals, doctors and other providers.</li> <li>Information related to your neighbourhood and where your child spends their time, like air pollution and childcare services near your home.</li> </ul>

**21) To what extent do you agree with the following statements about the information above:**

	Strongly agree	Agree	Neutral/ Mixed	Disagree	Disagree	Don't know/ Can't say
<b>I understand it</b>	Y	Y	Y	Y	Y	Y
<b>I feel positive about it</b>	Y	Y	Y	Y	Y	Y

<b>Randomised (1:1:1:1)</b>	
<b>Group A (Broad biosamples)</b>	<b>Group B (Limited biosamples)</b>
<p><b>Part 2 of GenV:</b>  <b>Bringing together samples already collected. These include:</b>            Samples collected from you before your baby was born and from you or your baby in the future. When you have a blood or urine test or a swab, the left-over sample is often stored for some months or years. With your permission, we transfer them to GenV and look after them carefully. The samples can then be used in research to benefit many families. Samples include:</p> <ul style="list-style-type: none"> <li>• The screening blood test you may have had at around 10-12 weeks of pregnancy - testing your baby for certain conditions</li> <li>• Your baby's newborn screening card (heel prick) – checking for rare conditions that can be treated. If you were born in Australia, we'd also like to access your own card if one exists.</li> <li>• Other routine samples you may have given during pregnancy, and samples you or your child may give going forward.</li> </ul>	<p><b>Part 2 of GenV:</b>  <b>Bringing together samples already collected. These include:</b>            Samples collected from you before your baby was born and from you or your baby in the future. When you have a blood or urine test or a swab, the left-over sample is often stored for some months or years. With your permission, we transfer them to GenV and look after them carefully. The samples can then be used in research to benefit many families. Samples include:</p> <ul style="list-style-type: none"> <li>• The screening blood test you may have had at around 10-12 weeks of pregnancy - testing your baby for certain conditions</li> <li>• Your baby's newborn screening card (heel prick) – checking for rare conditions that can be treated. If you were born in Australia, we'd also like to access your own card if one exists.</li> </ul>
<b>Group C (Broad biosamples mother only)</b>	<b>Group D (Broad biosamples child only)</b>
<p><b>Part 2 of GenV:</b>  <b>Bringing together samples already collected. These include:</b>            Samples collected from you before your baby was born and from you or your baby in the future. When you have a blood or urine test or a swab, the left-over sample is often stored for some months or years. With your permission, we transfer them to GenV and look after them carefully. The samples can then be used in research to benefit many families. Samples include:</p> <ul style="list-style-type: none"> <li>• The screening blood test you may have had at around 10-12 weeks of pregnancy - testing your baby for certain conditions</li> <li>• Your baby's newborn screening card (heel prick) – checking for rare conditions that can be treated. If you were born in Australia, we'd also like to access your own card if one exists.</li> <li>• Other routine samples you may have given during pregnancy, and samples you may give going forward.</li> </ul>	<p><b>Part 2 of GenV:</b>  <b>Bringing together samples already collected. These include:</b>            Samples collected from you before your baby was born and from you or your baby in the future. When you have a blood or urine test or a swab, the left-over sample is often stored for some months or years. With your permission, we transfer them to GenV and look after them carefully. The samples can then be used in research to benefit many families. Samples include:</p> <ul style="list-style-type: none"> <li>• The screening blood test you may have had at around 10-12 weeks of pregnancy - testing your baby for certain conditions</li> <li>• Your baby's newborn screening card (heel prick) – checking for rare conditions that can be treated. If you were born in Australia, we'd also like to access your own card if one exists.</li> <li>• Other routine samples your child may give going forward.</li> </ul>

**22) To what extent do you agree with the following statements about the information above:**

	Strongly agree	Agree	Neutral/ Mixed	Disagree	Disagree	Don't know/ Can't say
<b>I understand it</b>	Y	Y	Y	Y	Y	Y
<b>I feel positive about it</b>	Y	Y	Y	Y	Y	Y

<b>Randomised (1:1:1:1)</b>	
<b>Group A (Broad contact)</b>	<b>Group B (Limited contact)</b>
<p><b>Parts 3 and 4 of GenV:</b></p> <p><b>3. GenV would like to stay in touch.</b> Make brief contact with you from time to time to follow your and your child's health, development and wellbeing. For example, we may message or email you, or offer to assess your child face to face when older. You can decide at the time whether to take part. About 4 times per year, GenV will invite you to provide updates on how you and your child are going. Contacts may take between 3 and 20 minutes. You decide each time whether to complete them. Contacts may include:</p> <ul style="list-style-type: none"> <li>• Short surveys and updates that you fill out.</li> <li>• Health and development measurements. These cover things like memory games, speech in older children, and heart rate. For example, you might take a short video of your child, or you or your child might play a game on your electronic device (like your phone). They are as short and fun as possible.</li> <li>• News and updates from GenV. This may include invitations into studies working with GenV.</li> </ul> <p><b>4. GenV hopes to assess health and development face to face when your child is older.</b> Some health and development measurements can only be done face to face. We hope to visit all GenV children when they are older, for example when they start school. We haven't designed these visits yet. You can decide at the time whether to take part. We'll keep you well informed, so long as we can contact you.</p>	<p><b>Parts 3 and 4 of GenV:</b></p> <p><b>3. GenV would like to stay in touch.</b> Make brief contact with you from time to time to follow your and your child's health, development and wellbeing. For example, we may message or email you, or offer to assess your child face to face when older. You can decide at the time whether to take part. About 4 times per year, GenV will invite you to provide updates on how you and your child are going. Contacts may take between 3 and 20 minutes. You decide each time whether to complete them. Contacts may include:</p> <ul style="list-style-type: none"> <li>• Short surveys and updates that you fill out.</li> <li>• News and updates from GenV.</li> </ul> <p><b>4. GenV hopes to assess health and development face to face when your child is older.</b> Some health and development measurements can only be done face to face. We hope to visit all GenV children when they are older, for example when they start school. We haven't designed these visits yet. You can decide at the time whether to take part. We'll keep you well informed, so long as we can contact you.</p>
<b>Group C (Contact without measures)</b>	<b>Group D (Contact without invites)</b>
<p><b>Parts 3 and 4 of GenV:</b></p> <p><b>3. GenV would like to stay in touch.</b> Make brief contact with you from time to time to follow your and your child's health, development and wellbeing. For example, we may message or email you, or offer to assess your child face to face when older. You can decide at the time whether to take part. About 4 times per year, GenV will invite you to provide updates on how you and your child are going. Contacts may take between 3 and 20 minutes. You decide each time whether to complete them. Contacts may include:</p> <ul style="list-style-type: none"> <li>• Short surveys and updates that you fill out.</li> <li>• News and updates from GenV. This may include invitations into studies working with GenV.</li> </ul>	<p><b>Parts 3 and 4 of GenV:</b></p> <p><b>3. GenV would like to stay in touch:</b> Make brief contact with you from time to time to follow your and your child's health, development and wellbeing. For example, we may message or email you, or offer to assess your child face to face when older. You can decide at the time whether to take part. About 4 times per year, GenV will invite you to provide updates on how you and your child are going. Contacts may take between 3 and 20 minutes. You decide each time whether to complete them. Contacts may include:</p> <ul style="list-style-type: none"> <li>• Short surveys and updates that you fill out.</li> <li>• Health and development measurements. These cover things like memory games, speech in older children, and heart rate.</li> </ul>

<p><b>4. GenV hopes to assess health and development face to face when your child is older.</b> Some health and development measurements can only be done face to face. We hope to visit all GenV children when they are older, for example when they start school. We haven't designed these visits yet. You can decide at the time whether to take part. We'll keep you well informed, so long as we can contact you.</p>	<p>For example, you might take a short video of your child, or you or your child might play a game on your electronic device (like your phone). They are as short and fun as possible.</p> <ul style="list-style-type: none"> <li>News and updates from GenV.</li> </ul> <p><b>4. GenV hopes to assess health and development face to face when your child is older.</b> Some health and development measurements can only be done face to face. We hope to visit all GenV children when they are older, for example when they start school. We haven't designed these visits yet. You can decide at the time whether to take part. We'll keep you well informed, so long as we can contact you.</p>
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**23) To what extent do you agree with the following statements about the information above:**

	Strongly agree	Agree	Neutral/ Mixed	Disagree	Disagree	Don't know/ Can't say
<b>I understand it</b>	Y	Y	Y	Y	Y	Y
<b>I feel positive about it</b>	Y	Y	Y	Y	Y	Y

**Part 5 of GenV:**

**Tell services that you and your child are in GenV.** Other services may help GenV with short surveys or assessments during your normal visits to them. For example, your child's nurse might offer an extra vision test to your child. Sometimes you might move or your contact details might change. Services may be able to update GenV with your new contact details (unless we know you want to withdraw). Services include health and education providers like your Maternal & Child Health nurse, your doctor, hospitals, kindergartens and schools. We don't share your research data with these services.

**24) To what extent do you agree with the following statements about the information above:**

	Strongly agree	Agree	Neutral/ Mixed	Disagree	Disagree	Don't know/ Can't say
<b>I understand it</b>	Y	Y	Y	Y	Y	Y
<b>I feel positive about it</b>	Y	Y	Y	Y	Y	Y

<b>Randomised (1:1:1:1)</b>	
<b>Group A (Post consent broad)</b>	<b>Group B (Post consent swab only)</b>
<b>Part 6 of GenV:</b> If you agree to take part in GenV, we will ask you some questions and record your contact details. You can also consent for one or both of: <ul style="list-style-type: none"> <li>• A cheek swab from you and your child.</li> <li>• Use of samples (including the saliva from the cheek swab) for genetic research, to learn how genes influence health and development.</li> </ul>	<b>Part 6 of GenV:</b> If you agree to take part in GenV, we will ask you some questions and record your contact details. You can also consent for a cheek swab from you and your child.
<b>Group C (Post consent genetics only)</b>	<b>Group D (Post consent limited)</b>
<b>Part 6 of GenV:</b> If you agree to take part in GenV, we will ask you some questions and record your contact details. You can also consent for use of samples for genetic research, to learn how genes influence health and development.	<b>Part 6 of GenV:</b> If you agree to take part in GenV, we will ask you some questions and record your contact details.

**25) To what extent do you agree with the following statements about the information above:**

	Strongly agree	Agree	Neutral/ Mixed	Disagree	Disagree	Don't know/ Can't say
<b>I understand it</b>	Y	Y	Y	Y	Y	Y
<b>I feel positive about it</b>	Y	Y	Y	Y	Y	Y

## SECTION 7 – GENV GIVING FEEDBACK

The following is about what information GenV would give back to participants. Again, we are interested in your feedback on this information, so please read carefully.

<b>Will GenV give feedback on our health?</b> Where results might be helpful to you, GenV can give on-the-spot feedback when you or your child complete assessments. These short reports may suggest things are on track, or who you might see for advice if there are concerns. You can share these reports with others, like your doctor. After this immediate feedback, we won't individually check your or your child's stored data or samples for health problems. This means we don't provide further results. Other than the on-the-spot feedback, we don't provide later results from stored data or samples because: <ul style="list-style-type: none"> <li>• Research tests are not usually designed for treatment – doctors use different tests to treat patients</li> <li>• Results are not looked at for individuals – only as a group</li> <li>• Tests done years later may no longer be important or correct.</li> </ul> We encourage GenV researchers to report findings widely – this is how new knowledge gets put into practice. GenV will put summaries on its website. We hope this is helpful for parents. Only group results are published – never results for individuals.
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**26) To what extent do you agree with the following statements about the information above:**

	Strongly agree	Agree	Neutral/ Mixed	Disagree	Disagree	Don't know/ Can't say
<b>I understand it</b>	Y	Y	Y	Y	Y	Y
<b>I feel positive about it</b>	Y	Y	Y	Y	Y	Y

## SECTION 8 – GENV CONSENT AND DATA USAGE

The following information is about participating in GenV and how data would be used and protected. Again, we are interested in your feedback on this information, so please read carefully.

<b>Randomised (1:1)</b>	
<b>Group A (Join later)</b>	<b>Group B (No join later)</b>
<p><b>Do I have to take part?</b> No. It's up to you. Whatever you decide, it will not affect any care you or your child receive. However, the more people that take part, the more valuable the resource becomes.</p> <p><b>Can I change my mind later?</b> Yes, at any time. Just call or email us, or go to the GenV website.</p> <ul style="list-style-type: none"> <li>• If you consent now, you can withdraw later.</li> <li>• If you <u>don't</u> consent now, you can join GenV later. However, GenV will be missing information about your child's start to life.</li> <li>• When your child grows up (around age 14 to 18), they will have the opportunity to continue to take part as adults.</li> </ul>	<p><b>Do I have to take part?</b> No. It's up to you. Whatever you decide, it will not affect any care you or your child receive. However, the more people that take part, the more valuable the resource becomes.</p> <p><b>Can I change my mind later?</b> Yes, at any time. Just call or email us, or go to the GenV website.</p> <ul style="list-style-type: none"> <li>• If you consent now, you can withdraw later.</li> <li>• When your child grows up (around age 14 to 18), they will have the opportunity to continue to take part as adults.</li> </ul>

**27) To what extent do you agree with the following statements about the information above:**

	Strongly agree	Agree	Neutral/ Mixed	Disagree	Disagree	Don't know/ Can't say
<b>I understand it</b>	Y	Y	Y	Y	Y	Y
<b>I feel positive about it</b>	Y	Y	Y	Y	Y	Y

<p><b>How will GenV look after our information?</b></p> <p>Our Data Repository is purpose-built for GenV. No one can 100% guarantee the safety of any secure database. However, it is very hard to breach GenV's system. It is also against the law. Almost all of your GenV data are stored separately and securely from your personal information. This means that if there is a breach, people will not be able to link your health data with your name. This is to protect your privacy. Unless you tell us to remove it, we will keep your and your child's data indefinitely. This means GenV can support new discoveries for many years.</p> <p>GenV's Data Repository is held by the MCRI at the Royal Children's Hospital. Both are bound by Australian and Victorian privacy laws. Their data security and IT systems are reviewed and updated often. The next section tells you more about data security.</p> <p>GenV takes extra precautions for some information (like locations, images or genetic data) that could perhaps give hints about who is a part of GenV.</p> <p>You have the right to access and correct the personal information we collect and store about you and your child under privacy laws. You can do this by contacting GenV.</p>
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**28) To what extent do you agree with the following statements about the information above:**

	Strongly agree	Agree	Neutral/ Mixed	Disagree	Disagree	Don't know/ Can't say
<b>I understand it</b>	Y	Y	Y	Y	Y	Y
<b>I feel positive about it</b>	Y	Y	Y	Y	Y	Y

<b>Randomised (1:1)</b>	
<b>Group A (Companies)</b>	<b>Group B (No companies)</b>
<p><b>How do researchers use my data?</b></p> <p>GenV's data can only be used for research to improve health, development or wellbeing. Over time, researchers will use lots of different methods to answer new and important questions. Therefore, the value of your information will keep growing for many years. All GenV data are stored confidentially and in a secure space. Users can't make copies, so data are always in a secure and protected environment. Data users can include researchers, hospitals, policy analysts or companies. GenV has strict rules to review its data users.</p> <p>Approval for use is based on:</p> <ul style="list-style-type: none"> <li>• The research aims to improve health, development or wellbeing</li> <li>• GenV carefully assesses the researcher and the institution</li> <li>• Samples or data are used without identifying details – so there are no consequences for you.</li> </ul> <p>Some data and samples can only be analysed in specialised laboratories in Australia and around the world. Some of these laboratories need to operate commercially. This is common in research and has led to important discoveries. It happens under strict guidelines and laws, and the same rules for approval as above.</p> <p>When researchers work with data, they often create new data (eg from laboratory tests, or by combining data in new ways). These are added back into GenV. This creates more opportunities to improve health. Some GenV participants may also join research trials testing new approaches. Others may join studies or registries about specific issues (like head injuries or hearing loss). These trials or studies may ask your consent to share data between them and GenV. GenV supports this, so long as they are ethically approved.</p>	<p><b>How do researchers use my data?</b></p> <p>GenV's data can only be used for research to improve health, development or wellbeing. Over time, researchers will use lots of different methods to answer new and important questions. Therefore, the value of your information will keep growing for many years. All GenV data are stored confidentially and in a secure space. Users can't make copies, so data are always in a secure and protected environment. GenV has strict rules to review its data users. Data users can include researchers, hospitals or policy analysts.</p> <p>Approval for use is based on:</p> <ul style="list-style-type: none"> <li>• The research aims to improve health, development or wellbeing</li> <li>• GenV carefully assesses the researcher and the institution</li> <li>• Samples or data are used without identifying details – so there are no consequences for you.</li> </ul> <p>Some data and samples can only be analysed in specialised laboratories in Australia and around the world. Some of these laboratories need to operate commercially. This is common in research and has led to important discoveries. It happens under strict guidelines and laws, and the same rules for approval as above.</p> <p>When researchers work with data, they often create new data (eg from laboratory tests, or by combining data in new ways). These are added back into GenV. This creates more opportunities to improve health. Some GenV participants may also join research trials testing new approaches. Others may join studies or registries about specific issues (like head injuries or hearing loss). These trials or studies may ask your consent to share data between them and GenV. GenV supports this, so long as they are ethically approved.</p>

**29) To what extent do you agree with the following statements about the information above:**

	Strongly agree	Agree	Neutral/ Mixed	Disagree	Disagree	Don't know/ Can't say
<b>I understand it</b>	Y	Y	Y	Y	Y	Y
<b>I feel positive about it</b>	Y	Y	Y	Y	Y	Y

## SECTION 9 – REFLECTION ON THE INFORMATION PROVIDED

**30) Think about everything you've read here about GenV. How do you now feel about GenV?**

- ☐ Very positive
- ☐ Positive
- ☐ Neutral or Uncertain
- ☐ Negative
- ☐ Very negative

**31) What are the top 3 factors influencing your attitude toward GenV? (choose up to 3)**

*[randomise order]*

- ☐ Protection of privacy and confidentiality
- ☐ Potential benefits of GenV for me and my child
- ☐ Potential benefits of GenV for others like me and my child
- ☐ Potential misuse of data
- ☐ Time and effort involved for participants
- ☐ Risks versus benefits
- ☐ Wanting to contribute to research for the public good
- ☐ Trust in the organisations involved
- ☐ Use of biological or genetic samples
- ☐ Other, please describe...

**32) Based on all you've read, how confident would you feel about making a decision to participate in GenV or not?**

- ☐ Very confident
- ☐ Quite confident
- ☐ Not confident

**33) If you were invited to take part in GenV, what would you want to know more about in order to decide? (choose up to 5)**

*[randomise order]*

- ☐ The need for GenV
- ☐ Organisations and researchers involved
- ☐ Types of data collected
- ☐ Protection of privacy and confidentiality
- ☐ Use of biological samples (eg saliva)
- ☐ Who can access data
- ☐ How often participants will be contacted
- ☐ Withdrawing consent
- ☐ Funding sources
- ☐ How results will be communicated
- ☐ Other...

**34) Do you have any other comments about the information in this survey?**

[text box]

## SECTION 10 - PARTICIPATING IN FURTHER RESEARCH

GenV will be conducting further research into how it can communicate with parents. Would you be willing to take part in this research?

The research will consist of being provided with additional GenV communication materials (e.g. videos, brochures, consent forms) and being asked for feedback on those materials.

If you would like to be considered for this research, please indicate below.

Please note: this research is only about GenV's communication materials. Taking part does not mean that you are agreeing to be part of the GenV study itself.

- ☐ Yes, I would like to be considered for the next phase of GenV communication research
- ☐ No, I do not want to be considered