

GenV Parent/Guardian Information Statement

1. Why GenV?

GenV, short for Generation Victoria, is a state-wide research project. It will give a complete picture of the health and wellbeing of an entire generation.

All Victorian children born over a two-year period, and their parents, are invited to take part. We want to include all children and parents, no matter who they are or where they live. Every family matters - including yours.

GenV combines information you provide with data already collected by other services. This means it takes very little of your time. Future research can then find answers to complex health and wellbeing questions faster than we can today.

We hope GenV will help to prevent, predict and treat the issues facing children and parents today. We want to see less problems like diabetes, allergies, mental illness for everyone.

By being part of GenV, you can help create a better future for all families – now and tomorrow.

2. An invitation to take part in GenV

We invite you and your child to take part in GenV. To take part in GenV, you'll need to sign the consent form. You'll get a copy of this document and consent form to keep, and it is also at www.genv.org.au.

Before you decide, you should understand why GenV is happening and what it involves.

You can learn about GenV by reading this document or watching the video at www.genv.org.au. You can also contact us by email at genv@mcri.edu.au or free call 1800 436 888 (1800 GEN VVV). We are happy to answer your questions.

3. What is GenV?

GenV is the largest childhood research project ever in Australia. It is painting a picture of how children grow and develop, how people age, and how health changes across generations. It creates the building blocks to help researchers, communities and policy makers to improve health and wellbeing together. We hope it leads to better and safer care, and answers some of the most important questions facing our children and parents. GenV is open to over 150,000 children and parents across Victoria.

If you agree, we collect some information and samples from you and your child when you sign up to GenV, and as your child grows up. Then, with your permission, we add information and samples that services already collect in normal practice. We put this information in secure data systems that can be used in future research. Results can improve how we treat, predict and prevent problems. They can also help policy makers make good decisions to support Victorian families.

This means that GenV takes little effort from you, but creates meaningful change for families. We hope to study family health and wellbeing over many years.

Very big projects like GenV are already helping older adults around the world. We hope GenV will create these benefits for children and younger Victorians.

4. Who is conducting GenV?

GenV is led from the Melbourne Children's Campus (Murdoch Children's Research Institute, The Royal Children's Hospital, and The University of Melbourne). Funders have included the Paul Ramsay Foundation, the Victorian Government, The Royal Children's Hospital Foundation, the National Health and Medical Research Council and the Medical Research Future Fund. It is also supported by:

- Victorian birthing and local children's hospitals
- Victorian universities and research institutes
- leading experts in Victoria, Australia and around the world
- local families, services and communities, who have helped to design GenV.

The Scientific Director is Professor Melissa Wake, a paediatrician – that is, a children's doctor. You can read about her and the rest of the team [here](#).

5. Why are you asking us to join GenV?

You are invited because your child lives in Victoria and was born between 4th October 2021 and 3rd October 2023.

6. What does GenV involve?

GenV aims to make things as easy as possible for people who join. If you are willing to take part with your child, we ask you to give some information about your family, sign a consent form and fill in a short survey. This can take 10-20 minutes. We may give you a saliva swab to collect at home (see more below). If possible, we also invite your child's other parent/s. After this, GenV will stay in contact with you mainly by email, messaging or our GenV and Me App.

By taking part, you agree that GenV can:

(1) Bring together information and samples that already exist. These include:

- Information that services already collect for you and your child, from before your child was born and in the future. This includes information from your and your child's physical and mental health, education and social records and services, as well as birth and death information. GenV can access this from government departments, schools and kindergartens, and hospitals, doctors and other providers.
- Information related to your neighbourhoods, like air pollution and childcare services near your home.
- Samples collected by health services from you before your child was born and from you or your child in the future. When you have a blood or urine test or a swab, the left-over sample is often stored for some days, months or years. We can transfer them to GenV and look after them carefully. The samples can then be used in research to benefit many families.

You can read more about what we collect, who we collect it from, and how we used it at www.genv.org.au/for-parents.

(2) Make brief contact with you from time to time to follow your and your child's health, development and wellbeing. For example, we may contact you by email, message or App several times a year, or offer to assess your child face to face. You can decide at the time whether to take part.

(3) Safely access, store and use samples and information. We join up the information you give GenV with information from services like the ones above. These samples and information can be used in future ethically approved research that satisfies GenV's rules [See Sections 13 and 14 about storage of data].

(4) Tell services that you and your child are in GenV.

You can also choose whether or not to give your consent for:

- (5) **A saliva swab** from inside the cheek from you and your child. Saliva swabs can support different kinds of biological research, including genetic research. *Read more about saliva swabs [here](#).*
- (6) **Use of samples (eg saliva swab or newborn screening card) for genetic research**, to learn more about how genes interact with other factors to influence health and development. This might help researchers answer new questions, eg about how conditions and risk factors are passed on from parents to children. In the future, new technology might allow for other kinds of tests. *Read more about genes [here](#).*

What kinds of information will GenV access with my permission?

Some examples are:

- Physical and mental health: eg Medicare, hospital records, copies of digital scans like ultrasounds, information collected about your pregnancy
- Education: eg national literacy and numeracy assessments at school, if your child takes part
- Social: eg disability, child care support/welfare, housing, justice
- General information about your neighbourhoods: eg childcare locations, air pollution.
- Your or your child's unique identifier numbers for the above, eg Medicare, student numbers.

Read more about GenV's data sources [here](#) and see the data sources we access each year at www.genv.org.au.

What kinds of routine samples will GenV access with my permission?

Samples include:

- The screening blood test you may have had at around 10-12 weeks of pregnancy - testing your child for certain conditions. Read more about the 10 week screen [here](#).
- The blood sample from your child's newborn screening card (heel prick) – checking for rare conditions that can be treated. If you were born in Australia, we would also like to access your own card if one exists. Read more about the newborn screening card [here](#).
- Other routine samples you may have given during pregnancy, and samples you or your child may give going forward.

You can read more about GenV's routine samples [here](#) and see the samples we access each year at www.genv.org.au.

What happens when GenV contacts me?

About four 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:

- short surveys and updates that you fill out.
- 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. Read more about GenV measures [here](#).
- news and updates from GenV. This may include invitations into studies working with GenV.

Read more about studies working with GenV [here](#).

What about GenV assessments when children are older?

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. *Read more about GenV visits [here](#).*

Why does GenV tell services that my child and I 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, give you feedback, and record the result. 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 may include health and education providers such as your Maternal & Child Health nurse, your doctor, hospitals, Medicare, Centrelink, kindergartens, or schools.

We do not share your research data with them. *Read more about services working with GenV [here](#).*

7. What are the benefits of joining GenV?

GenV may or may not directly benefit you or your child.

We can give on-the-spot feedback when you or your child complete surveys or assessments. You may find this helpful (see section 11).

Over time, GenV will report on many issues relevant to children and parents in general. We hope that GenV will help improve the lives of many children and parents. We will share these overall results with you, and hope they are useful to you.

8. How do we join GenV?

You sign the consent form, and we send you a copy to keep. You can take part in all or some of GenV. Where possible, we hope all parents will take part. You provide consent for yourself. One parent/guardian also provides consent for your child.

9. Do we have to take part?

No. It's up to you. Whatever you decide, it will not affect the care you or your child receive. However, the more people that take part, the more valuable GenV becomes.

10. Can I change my mind later?

Yes, you can change your mind at any time. Just call or email us or go to the GenV [website](#). You do not need to tell us the reason for your decision.

- If you consent now, you can withdraw later. *Read more about withdrawing [here](#).*
- If you do not consent now, you can join GenV later. However, GenV will miss the earlier information from you and your child. *Read more about joining later [here](#).*
- When your child grows up (around age 14 to 18 years), they will have the opportunity to continue to take part as adults. *Read more about continuing with GenV [here](#).*

11. Will GenV give feedback on our health?

When you or your child completes assessments, GenV can give you on-the-spot feedback of results that might be helpful to you. 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.

Other than on-the-spot feedback, we do not individually check new data generated later from your or your child's stored data or samples. This means GenV does not provide these later results to you.

This is because:

- research tests are not usually designed for treatment – doctors use different tests to treat patients
- research does not look at results for individuals – only for groups
- tests done years later may no longer be important or correct.

GenV may offer you the chance to take part in future ethically approved studies working with us. It is possible they may give extra feedback. You can always choose whether to take part.

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 individual results.

12. What are the risks of joining GenV?

Joining GenV should not cause any harm or affect the care that you or your child receive. GenV has strict and secure systems to protect your privacy. This means the risk of a data privacy breach is very low.

We understand that joining GenV takes trust. Trust by parents like you has led to many discoveries that help children and adults today, in areas like infection and cancer. We will work hard to repay your trust.

13. How will GenV look after our information?

Our data systems are purpose-built for GenV. It is very hard for unauthorised people to access GenV's systems. It is also against the law. We store all information in secure environments and perform regular testing. We also protect privacy by removing identifying details (like names) from the data researchers use.

We use your personal information (like your name, contact details and identifier numbers) to run GenV. This is how we stay in touch with you. Also, when we access other datasets (Section 6), this information is used to ensure we are matching to the right person. To see our Privacy Collection Notice and MCRI's Privacy Policy visit www.genv.org.au/privacy. You have the right to access and correct the personal information we store about you and your child under privacy laws. You can do this by contacting GenV.

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.

The Murdoch Children's Research Institute is bound by Australian and Victorian privacy laws. It updates its data security and IT systems, processes and policies regularly. For research purposes, GenV research data may also be placed in systems held by other authorised agencies. These have the same level of security and privacy.

Read more about GenV's data security [here](#) and handling your personal information [here](#).

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. Read more about GenV's precautions [here](#).

14. How do researchers use our data?

GenV's data can be used for research to improve health, development or wellbeing for children and adults. It must be covered by ethical approval. 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 used confidentially. GenV has strict rules about security and who can use its data.

Approval for use is based on:

- The research aims to improve health, development or wellbeing
- The proposed use of the data has ethical approval
- GenV assesses the safety and expertise of the applicant and the institution or organisation
- Samples or data are used without identifying details – so data users do not know they belong to you.
- Users agree to GenV's conditions of use.

Read more about approval [here](#).

The GenV team also uses your data to check GenV's progress and quality and test the datasets. Some data and samples can only be analysed in specialised laboratories in Australia and around the world. This is common in research and has led to important discoveries. Sometimes their use is covered by laws in countries outside Australia. They happen under strict guidelines, and the same rules for approval as above.

When researchers work with data, they often create new data from laboratory tests, or by combining data in new ways. These are added back into GenV. This creates more opportunities to improve health.

Commercial companies can apply to use GenV's data for research to improve health, development or wellbeing. They must meet the same approval rules.

Some GenV participants may join research trials testing new approaches. All trials need ethical approval. Who is offered the new approach is usually randomly picked, like tossing a coin. In some trials, only people offered the new approach are contacted about taking part. GenV data can be used to compare the outcomes of people who do and do not receive the new approach. GenV participants may also join studies or registries about specific issues such as head injuries or hearing loss. Trials or studies may ask your consent to share data with GenV, with ethics approval. We support this.

15. More questions? Any concerns?

The GenV [website](#) has answers to many questions. It also has this Information Statement.

To contact a member of GenV, please call 1800 436 888, email genv@mcri.edu.au or contact us by the [website](#). You can also speak to someone independent of the project about any concerns or complaints, how it's conducted, or your or your child's rights as a participant. Please contact the Director of Research Development & Ethics at The Melbourne's Royal Children's Hospital on (03) 9345 5044 or rch.ethics@rch.org.au.

**Thank you for considering taking part in GenV.
We hope you join GenV on this journey.**