

Parent/Guardian Volunteer Information Sheet for Generation Scotland

Information for Parents & Guardians

Generation Scotland is a **family study** [FAQ link], we follow the health and wellbeing of multiple generations of families over time. If you are a parent or guardian of a child aged 12-15, you can also invite them to join Generation Scotland. In order for them to join, they must have their own email address, so that we can contact them.

If you are interested in inviting your child or ward to take part, we have some further information to share. If you do not want to do this now, you can return to this page through the volunteer portal at any time.

Are you a parent or guardian of a child aged 12-15, and would you like to invite them to join Generation Scotland?

[Multiple choice – radio buttons]

Yes	(1)
No	(0)

If yes:

If you agree, we will contact your child using the details you provide. We will give your child information to read to help them decide if they would like to take part in the study. They can still choose not to take part. This will not affect your involvement as a volunteer. They can also choose to stop taking part at any time.

If you have more than one child aged 12-15 years old then you can invite them by adding each of them to the same digital consent form. There is the option to add more children at the start of the form, or add more children in the future as they become eligible.

As their **parent or guardian** you are best placed to judge their ability to take part. By agreeing to your 12-15 year old(s) joining Generation Scotland you would be confirming that you think they will be able to fully understand what they would be agreeing to and what it means for them. We call this 'capacity, or 'competence to give consent'.

Just as we ask adults about sensitive topics, we also ask young people about sensitive topics. These questions may include alcohol use,

smoking, how they feel about food, their body, gender identity and bullying. They may choose to skip any questions they do not wish to answer during the questionnaire. The whole list of questions is available at the link below. They should be given privacy to complete the questionnaire, and their answers will not be shared with to you.

LINK

This study is for research purposes only and is not a pathway to clinical treatment. As we mentioned when you joined the study, we are unable to give individual feedback. We provide useful resources and contact details of organisations who support young people and families on some of the topics mentioned in the study below.

LINK

We have also taken some extra steps to make sure young people understand what they are agreeing to:

- **12-15 year olds** can only join Generation Scotland if a parent or guardian is a volunteer and has agreed they can take part.
- **12-15 year olds** will be asked 2 questions after they read through our volunteer information. This isn't to test them, it's to make sure we explain our study well. They shouldn't worry if they get one question wrong. They can reread the information page and try again. If there's anything they want explained further, they can always [contact us](#) for more information.

Click the link below to see copies of the Volunteer Information and Consent forms for 12-15 year olds.

LINK

Please press next to invite your 12-15 year old.

Parent/Guardian Consent Form for Generation Scotland

Name:

Date of Birth:

Email address:

Please read the following statements and tick the boxes to agree

I confirm that I have read and understood the Generation Scotland Parent/Guardian Information for taking part in Generation Scotland and have had the opportunity to ask questions.

Insert name(s), email address(es) and date of birth(s) of each child (or ward) you wish to be invited to take part in Generation Scotland:

(expanding form +add child line on form)

1.Name:(type in child's name) Email (type in child's email) Date of birth (type in child's date of birth)

2.Name:(type in child's name) Email (type in child's email) Date of birth (type in child's date of birth)

3.Name:(type in child's name) Email (type in child's email) Date of birth (type in child's date of birth)

4.*(Add child)*

For each child named above:

I understand that as my child named above is not yet 16 years of age I must provide agreement for them to take part in Generation Scotland.

I confirm that my child named above has the capacity, or competence to understand the full nature of what they are agreeing to.

I understand that my child's participation in this project is voluntary and that my child is free to withdraw at any time, without giving any reason, and without their medical care or legal rights being affected.

I agree to let my child give a saliva sample for research to be tested as outlined in the information sheet. I understand that this testing will include analysis of my child's genetic code.

I agree to the storage and study of any of my child's surplus samples (e.g. blood, urine or other tissue) remaining after any routine clinical testing by the NHS.

I agree to my child's past and future health, health-related and administrative records being shared with Generation Scotland. I agree to the use of this information and other information about my child for health-related research purposes and to keep in touch with my child.

I agree to have my child's samples and data analysed and stored in a secure and anonymised way under the control of the Generation Scotland team, and used for approved health research.

I understand that my child's data and samples may be shared with other researchers by the Generation Scotland team through an approved access process. This may include researchers working abroad, or working for commercial companies. Research will only be approved where it is clearly in the public interest.

I understand my child will not benefit financially from taking part (e.g. if research leads to commercial development of a new treatment).

I understand that if my child loses their mental capacity or dies then their samples and data will continue to be used in approved research studies.

I agree to my child's General Practitioner being informed of their participation in the study.

I agree to my child being contacted by the Generation Scotland team to complete additional questionnaires or to invite them to participate in other health related studies, including donating further samples. I understand that this will not commit them in any way to taking part in further research, and that my child can withdraw consent for recontact at any time.

I understand that my child may be invited to participate in other studies based on data held or accessed about them, and/or analysis (including DNA markers) of samples my child has donated.

I understand that Generation Scotland will not feedback any genetic results, as my child's (or ward's) samples are taken for research purposes only.

I agree to my child taking part in Generation Scotland and that by checking this box I am providing my signature to this agreement.