

## Parent/Guardian Volunteer Information Sheet for Generation Scotland

### Information for Parents & Guardians

Generation Scotland is a **family study** [FAQ link]. We track the health and well-being of all types of families over time. If you are a parent or guardian of a child aged 12—15 years you can also invite them to join Generation Scotland. In order for them to join, they must have their own email address or mobile phone number, so that we can contact them.

If you are interested in inviting your child/young person 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 young person aged 12—15 years, and would you like to invite them to join Generation Scotland?

If you agree, we will contact your child/young person using the details you provide. We will give your child/young person 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, either by declining the invitation or by just not replying. 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/young person aged 12—15 years then you can invite each of them by adding them to the same digital consent form. There is the option to add more children/young people at the end of the form or to add more children/young people in the future as they become eligible.

As their **parent or guardian**, you are best placed to judge their capacity 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 (for the young person) to give their own consent’.

Just as we ask adults about sensitive topics, we also ask young people about sensitive topics, like alcohol use, smoking, feelings about food, body image, gender identity and bullying. They can 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 you.

LINK

This study is for research only and is not for clinical treatment or genetic testing. As we mentioned when you joined the study, we are unable to give individual feedback. We provide useful resources and contacts for supporting 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 has assessed their capacity and agreed they can take part.
- **12–15-year-olds** will be asked a short true/false style a question after they read through our volunteer information. This is not a test. This is not a test but does ensure we are explaining our study in a way that young people understand and know what is involved They should not worry if they get the question wrong. They can read the information page and try again. If there is anything you or they would like explained further, [contact us](#) for more information.

If you want to see copies of the Volunteer Information and Consent forms for 12–15-year-olds then please click the link below

Your child will not be paid for joining the study, but they will be compensated for their time. We offer all people in the study aged 12–18 years a £20 e-voucher card (Amazon or Love2shop or equivalent) after they have joined the study and posted back their saliva sample. We are not able to offer compensation to all age groups in our study, so we have focussed on offering it to those who are aged 18 and under as they currently make up less than 2% of our volunteers. We believe it is important to include young people in our study to help us better understand the unique challenges faced by this generation, including the Covid-19 pandemic, climate change and the cost-of-living crisis.

We also know that joining Generation Scotland requires time. For young people, making time to volunteer may be especially challenging as most are in school/training and do not receive a regular income.

While we cannot offer compensation to everyone in the study, the main benefit for both adults and young people is helping research that could lead to better health care in the future. [LINK](#)

Please press Next to invite your 12–15-year-old. This invitation will expire after 28 days, and you will have to re-invite them if they change their mind and want to join after their invitation has expired.

## Parent/Guardian Volunteer Consent Form for Generation Scotland

Please read the following statements and <u>tick</u> the boxes to agree	Tick
I confirm that I have read and understood the Generation Scotland Parent/Guardian Information and the 12-15 year old Information for taking part in Generation Scotland and have had the opportunity to ask questions.	
I confirm that my child/young person has the capacity, or competence to understand the full nature of what they are agreeing to which includes:	
<ul style="list-style-type: none"><li>• Their participation is voluntary and they are free to withdraw at any time.</li><li>• They will give a saliva sample to be tested as outlined in the information sheet which will include analysis of their genetic code.</li><li>• Their surplus samples (e.g. blood, urine or other tissue) remaining after any routine clinical testing by the NHS may be stored and analysed by the study.</li></ul>	

<ul style="list-style-type: none"> <li>• Their past and future health, health-related and administrative records may be shared with Generation Scotland. I understand this information and other information about my child/young person will be used for health-related research purposes and to keep in touch with my child/young person.</li> <li>• Their samples and data will be analysed and stored in a secure and anonymised way under the control of the Generation Scotland team and used for approved health research.</li> <li>• Their 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.</li> <li>• Other than an e-voucher, they will not benefit financially from taking part (e.g. if research leads to commercial development of a new treatment).</li> <li>• That if they lose their mental capacity or dies then their samples and data will continue to be used in approved research studies.</li> <li>• Their General Practitioner will be informed of their participation in the study.</li> <li>• They may be 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/young person can withdraw consent for recontact at any time.</li> <li>• They 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/young person has donated.</li> <li>• That Generation Scotland will not feedback any genetic results, as my child/young persons samples are taken for research purposes only.</li> </ul>	
<p>I confirm that my child/young person does have the capacity, or competence to understand the full nature of what they are agreeing to and by ticking this box I am providing my signature to confirm my child/young person has the capacity to decide if they wish to take part in Generation Scotland.</p>	

(Expanding form + add child line on form)

Name (type in child's name)	Preferred method of contact [Dropdown menu - Email, Phone (text)]	Type in child's contact details twice	Date of birth (type in child's date of birth)