

Parent/Guardian Non-Volunteer Information Sheet for Generation Scotland

Information for Parents & Guardians

Generation Scotland is Scotland's largest **family health study**, where we track the health and wellbeing of all types of families over time. So far 36,000+ volunteers have already helped research into cancer, dementia, diabetes, mental health and many other health conditions using DNA. Anyone aged 12 and over who lives in Scotland can join the study.

However, you do not have to be part of a family to join our study. You can join as an individual.

More information about Generation Scotland can be found at www.generationscotland.org

Your child/young person has requested to join Generation Scotland, but as their **parent or guardian** you are best placed to judge their capacity to take part. They can only fully join the study if you think they understand what joining involves.

Your child/young person's understanding:

If you agree to your 12–15-year old's request to join Generation Scotland please complete the form below. You will be confirming that you think your young person/child is able to fully understand the questions they have been asked and what they have agreed to do. We call this 'capacity', or 'competence' – those ages 12-15 must obtain confirmation of capacity/competence from a parent/guardian to take part in the study.

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 to answer a short true/false style question after they have read through our volunteer information. 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.

What your child/young person will be asked to do to take part:

In order to join your child/young person needs to:

- Read the volunteer information
- Ask us any questions
- Complete consent form (15 checkboxes)
- Provide contact details for their parent/guardian and discuss with them why they want to join Generation Scotland.
- Fill out the questionnaire about their health and wellbeing (15 mins max)
- After they complete the questionnaire, and their parent/guardian agrees, they will receive a DNA saliva kit in the post.
- They complete the saliva sample and return it for free by dropping it in any postbox. That is it, they've joined..

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 (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.

Read the 12–15-year-old information:

Here is a link to read the Volunteer Information and Consent forms for 12–15-year-olds that your child/young person must read before agreeing to join Generation Scotland. We would like you to assess your child/young person's ability to understand this information and then fill out the form below.

LINK

You can also read a copy of the questions they will be asked as part of the study here:

LINK

This study is for research only and is not for clinical treatment or genetic testing. 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

What we need you to do:

If you feel your child/young person has the capacity to agree to join Generation Scotland, then please fill out the form below.

If you feel your child/young person does not have the capacity to agree to join Generation Scotland, please tick that option at the bottom of the form. If you confirm your child/young person does not have the capacity to join Generation Scotland, all of the information provided by you and your child will then be deleted by the Generation Scotland Team.

You have 28 days to decide whether you agree your child/young person can join Generation Scotland. We will send you and your child/young person some reminders that we need you to complete this form.

If we do not hear from you at the end of the 28 days, all of the information provided by you and your child/young person will then be deleted by the Generation Scotland Team.

If you have any questions, please call us on 0131 651 8718 or email us at genscot@ed.ac.uk

You can find more information about us at www.generationscotland.org

Parent/Guardian Non-Volunteer Consent Form for Generation Scotland

First Name:

Last Name:

Child/Young person's First Name:
Name:

Child/Young person's Last

Please read the following statements and tick 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:

- Their participation is voluntary and they are free to withdraw at any time.
- They will give a saliva sample to be tested as outlined in the information sheet which will include analysis of their genetic code.
- 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.
- 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 will be used for health-related research purposes and to keep in touch with my child/young person.
- 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.
- 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.
- 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).
- That if they lose their mental capacity or dies then their samples and data will continue to be used in approved research studies.
- Their General Practitioner will be informed of their participation in the study.

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- 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.
 - 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.
 - That Generation Scotland will not feedback any genetic results, as my child/young person's samples are taken for research purposes only.

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.

OR

I confirm that my child/young person does **not** 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 they **cannot** take part in Generation Scotland.