

New Volunteer 12-15 year old Volunteer Information Sheet and Consent

Thank you for your interest in joining Generation Scotland.

To confirm you are eligible to join we need you to answer a few questions.

Are you:

- 12—15 years old
- 16–18 years old
- Aged 19 or older

Do you currently live in the United Kingdom?

This includes Scotland, England, Wales, and Northern Ireland.

- Yes
- No

Do you currently live in Scotland or do you have a relative who is a current Generation Scotland volunteer?

- Yes
- No

Thank you for answering these questions and confirming you are eligible to join Generation Scotland.

What is Generation Scotland?

We are Scotland's largest **family health study**. We track the health and wellbeing of all types of families over **time**.

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

So far 36,000+ volunteers have already helped research into cancer, dementia, diabetes, mental health and other health conditions using DNA.

Commented [LK1]: Text redrafted to make more straightforward/inclusive

Commented [LK2]: New addition to VIS due to this being a frequent volunteer question

New Volunteer 12-15 year old Volunteer Information Sheet and Consent

We are excited to include young people in our study to help make positive changes for the future.

Please keep reading to learn more about us and what is involved. Taking part is voluntary and you can stop at any time without giving a reason.

Commented [LK3]: This sentence has been moved further up

At the end we will ask a question to check that you understand what you are signing up for. This is to make sure we have explained our study properly. It is not a test.

If you need more help, or 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

Who can take part?

Anyone aged 12 and over who lives in Scotland can take part. You can sign up online anytime. You do not need to visit a health centre.

For 12- to 15-year-olds a parent or guardian needs to agree that you can join Generation Scotland. As it is a long-term study, they need to double check that you understand what you are signing up for.

What will I be asked to do?

- **Finish reading this information**
- **Ask us if you have any questions**
- **Complete the consent form (15 checkboxes)**
- **Provide contact details for your parent/guardian (name, email/mobile number & postcode) and let them know you want to join.**
- **Fill out the questionnaire about your health & wellbeing (15 mins max)**
- **After you complete the questionnaire, and your parent/guardian also agrees, a saliva sample kit will be sent to your home. Your 'spit kit'!**

New Volunteer 12-15 year old Volunteer Information Sheet and Consent

- Complete the saliva sample and return it for free by dropping it in any postbox. That is it, you've joined!

More info [DROP DOWN]

Once you have agreed to join Generation Scotland, we will ask for your parent or guardian's email address or mobile number and postcode, so we can ask them if they agree for you to join.

We send them a link to read the information we provided you. Then we ask them if they agree for you to join. If they do not agree you will not be able to join Generation Scotland and all the information we hold about you will be deleted. If this is the case you may choose to join at a later date. All 16-year-olds and over may join without a parent/guardian involvement.

Once you finish the online consent, you can start the **questionnaire**, which asks about your health and wellbeing. You can do it right away or return to it later if you like. It takes about 15 minutes to do.

All of our volunteers can use our online portal to update personal details and access future questionnaires. [END DROP DOWN]

Will I be paid?

You will be compensated for your time with a £20 e-voucher card. It is your choice if you would like to accept the e-voucher. You will receive it after you have finished the questionnaire and returned the saliva sample.

Commented [LK4]: New text to explain young person compensation

Benefits of taking part:

- Researchers can **learn more** about **youth mental health** and other health conditions, which could lead to new treatments and cures.
- We will keep you **updated** about our findings through our website, social media and e-newsletters.
- By joining you become part of a community helping to shape future research.

Possible challenges of taking part:

- The first questionnaire takes about **15 minutes**, but you can take a break and return any time.

New Volunteer 12-15 year old Volunteer Information Sheet and Consent

- Providing a saliva sample is a simple procedure, and you will receive step-by-step instructions, but some people might find it difficult.

We may ask about sensitive topics like alcohol use, smoking, feelings about food, body image, gender identity and bullying. You can skip any questions you do not want to answer.

What information do we collect?

We track the health of our volunteers by accessing **official records**, which may include:

- **NHS health records** such as: medications, vaccinations, hospital admissions, dentists, previous illnesses, appointments.
- **Administrative records** such as: records from Education Scotland, the Tax Office and the Department of Work and Pensions.

The types of official records available **can change over time**. In future, we may access more administrative records than we have suggested in this information sheet.

As we establish links to new official records **we will update you** on the type and what information it holds, although we won't be able to provide you with specifics. If you feel uncomfortable about any new linked record, please **reach out to us**.

Additionally, when/if doctors or nurses take samples to test, for example blood or urine samples, there is often some surplus left over. We may ask the NHS to keep the leftover sample for our research.

How do we link your data?

We access official records through a process called 'data linkage'. Data linkage is a safe and secure way to access official records and is used by many researchers across the UK.

How will my information, sample and data be stored and kept safe?

The Generation Scotland team will store your samples and data securely at a safe location at the University of Edinburgh, using a unique ID number instead of your personal details.

We follow General Data Protection Regulations (GDPR) to keep your information safe.

New Volunteer 12-15 year old Volunteer Information Sheet and Consent

We will **not share** your answers or data with:

- Your parent/guardian
- Your school
- Your current or future places of work
- Insurance companies
- Anyone other than approved researchers.

Who will be able to use my information and samples?

- The Generation Scotland team
- Approved researchers

All research must be ethically approved to benefit the public. Researchers may be from the NHS, universities, commercial companies or charities and they can be based in other countries.

We will let your GP know you are taking part in Generation Scotland, because we will request access to your health records.

Will I get information about my results?

No. This study is for research only and is **not for clinical treatment or genetic testing**. However, we provide useful resources and contacts for supporting young people and families on some of the topics covered in the study **here [link]**.

You can choose to take part or not.

Additional information about results [DROP DOWN]

We will not return results or provide information to you about your genetics. Instead, your information will help scientists and researchers learn more about health conditions, cures and treatments for the population of Scotland in the future.

Genetic tests on your samples are for research only. They are not reliable for identifying a disease or condition. **[END DROP DOWN]**

What happens after you join?

You might be contacted about new studies in the future. **These are always optional to join.**

New Volunteer 12-15 year old Volunteer Information Sheet and Consent

You may be asked to join other studies based on:

- Information you have given (e.g. questionnaires)
- Information in your official records
- Genetic information from your saliva sample. We get this information from the DNA in your sample. DNA is found in people and all other living things. Our genes are made of this DNA. It helps determine what we look like and our chances of getting certain conditions.
- We often need a mix of people, including healthy people to match someone with a condition researchers are interested in.

If you have any concerns, please do not hesitate to get in touch with us.

Has Generation Scotland been checked as safe and secure?

Before health research can start it must be looked at carefully by a Research Ethics Committee. Their job is to protect your safety, rights and well-being. The **NHS East of Scotland Research Ethics Committee** reviewed and approved our project.

What if I want to stop taking part?

You can stop taking part at any time by contacting us by phone or email. You do not have to give a reason if you do not want to.

There are two types of withdrawal you can request:

1) No further contact: We will not contact you with updates or future study requests, but we can still use the information, samples and official records you gave.

2) No further use: In addition to “no further contact,” we will not use your information and samples for new research, but this does not include ongoing or finished research.

Question

This is not a test. We just need to check you understand and are happy to join Generation Scotland.

Tick **all** the statements which you think are **TRUE?**

Commented [LK5]: Change to question so that all answers are true after feedback from some young people that the question was confusing. Also addition of option to reflect voucher offer.

1. I will provide a saliva sample using a kit sent to my home.

New Volunteer 12-15 year old Volunteer Information Sheet and Consent

2. I will be compensated for my time by means of an e-gift card
3. Generation Scotland will link to my NHS Health Records.
4. Generation Scotland may share my data and sample anonymously with approved researchers.
5. I can leave the study at any time.
6. Once I have signed up to Generation Scotland, they will keep me updated on what they are doing.

Contact details

If you have any questions, or concerns, please contact us using the details below:

Email: genscot@ed.ac.uk

Tel: 0131 651 8718 9am - 4pm Monday to Friday

You can also find more information on our website ([link](#))

Generation Scotland
University of Edinburgh
Institute of Genetics and Cancer
Western General Hospital
Crewe Road South
Edinburgh
EH4 2XU

12 to 15 Volunteer Consent Form for Generation Scotland

Please read the following statements and tick the boxes to agree

New Volunteer 12-15 year old Volunteer Information Sheet and Consent

I confirm that I have read and understood the volunteer information for taking part in Generation Scotland and have had the opportunity to ask questions.

I understand that as I am not yet 16 years of age, I must have the agreement of my parent or guardian to take part.

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

I agree to 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 genetic code.

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

I agree to my 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 me for health-related research purpose and to keep in touch with me.

I agree that my samples and data can be 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 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.

New Volunteer 12-15 year old Volunteer Information Sheet and Consent

Other than an e-voucher, I understand that I will not benefit financially from taking part (e.g. if research leads to commercial development of a new treatment).

Commented [LK6]: Slight change to one consent question to reflect voucher offer

I understand that if I should lose my mental capacity or in the unlikely event of my death then my samples and data will continue to be used in approved research studies.

I agree to my General Practitioner being informed of my participation in the study.

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

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

I understand that Generation Scotland will not feedback any genetic results, as my samples are taken for research purposes only.

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

Registration

First Name(s):

Last Name:

New Volunteer 12-15 year old Volunteer Information Sheet and Consent

Date of Birth: Day/ Month/ Year

I would like to receive a £20 e-voucher as compensation for my time spent joining Generation Scotland: Yes No

Commented [LK7]: Option to accept or reject voucher

Please select whether you would like to login using an:

Email address:

Confirm Email address:

Phone number (text message):

Confirm phone number:

Your password must be at least 7 characters long, including 1 uppercase letter, 1 lowercase letter, and 1 numeric value.

Password:

Re-enter Password: Parent/Guardian contact information:

First Name(s):

Last Name:

Postcode:

Please select whether you would like us to contact your parent or guardian using an:

Email address:

Confirm Email address :

Phone number (text message):

Confirm phone number:

I confirm this person is my legal parent or guardian.

<REGISTER>