

19+ Volunteer Information Sheet for Generation Scotland

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 already a Generation Scotland volunteer?

- Yes
- No

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

This information sheet contains important information about the Generation Scotland project and what your participation would involve. It may take around 20 minutes to read. Please read through this carefully before deciding if you would like to take part.

What is Generation Scotland?

We are Scotland's largest **family health study** and 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 many other health conditions using DNA. 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.

Please keep reading to learn more about us and what is involved. If anything is not clear, you can call us on **0131 651 8718** or email us at **genscot@ed.ac.uk**

You can also find more information on our website www.gen.scot

Who can take part?

Anyone aged 12 and over who lives in Scotland can join, although 12-15 year olds need a parent or guardian to agree for them to join. You can sign up online anytime and you don't need to visit a health centre.

If you are 16 or older and live in Scotland, you can join on your own.

If you live in England, Northern Ireland or Wales, and are related to someone in Generation Scotland, you can join too.

What will I be asked to do?

- **Finish reading this information**
- **Ask us if you have any questions**
- **Complete the consent form (15 checkboxes)**
- **Fill out the questionnaire about your health & well-being (around 20 minutes)**
- **You will then receive your DNA saliva sample kit in the post (your 'spit kit').**

- **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 finish the online consent, you can start the **questionnaire**, which asks about your health and wellbeing. You do it right away or return to it later if you like - it takes about 20 minutes to do.

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

Benefits of taking part:

- Researchers can **learn more** about health conditions such as chronic pain, diabetes, mental health and dementia, which could lead to new treatments and cures.
- Although you will **not be paid**, findings from this research could **benefit you and society** for years to come.
- We will keep you **updated** about our findings, through our website, social media and newsletters.
- By joining you become part of a community helping to shape future research.

Possible challenges of taking part:

- The first questionnaire takes about **20 minutes** to do, but you can take a break and return any time.
- 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 you about sensitive topics like alcohol use, smoking, your diet, ongoing health conditions, and gender identity. You can skip any questions you don't want to answer. Your answers will only be shared anonymously outside the GS team with approved researchers.

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.

Your identity will be protected and the information accessed will only be used for research purposes without altering your individual healthcare, education, pension or benefit provision.

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.

Will I be paid?

You will not be paid to join Generation Scotland. We do now however offer a £20 e-gift voucher to people aged 12–18 who take part.

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, who currently make up less than 2% of our volunteers.

We know joining Generation Scotland requires time. For young people especially, making time to volunteer may be particularly challenging as

most are in school/training and do not receive a regular income. This voucher is in line with other studies involving those aged 18 and under.

We asked some of our adult volunteers and they agreed that it is important to include young people in health studies like Generation Scotland. They accepted the importance of offering voucher compensation to this age group to increase their representation in the study.

How do we store and protect your data and DNA sample?

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.

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

- Your relatives
- 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. 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, it 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 done 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.

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.
- 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 that can be requested:

- 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. This does not include ongoing or finished research.

Contact details

If you have any questions, concerns or complaints, 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 **www.gen.scot**

Generation Scotland

University of Edinburgh

Institute of Genetics and Cancer

Western General Hospital

Crewe Road South

Edinburgh

EH4 2XU

19+ Volunteer Consent Form for Generation Scotland

Please read the following statements and tick the boxes to agree

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 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 confirm that I live in Scotland or have a family member who is already a part of Generation Scotland who lives in Scotland.

I agree to give a saliva sample for research that will 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 purposes and to keep in touch with me.

I agree that my samples and data can be stored and analysed, 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.

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

I understand that if I lose my mental capacity or die 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. I understand that this does 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 return any genetic results to me, as my samples are taken for research purposes only.

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

Registration

First Name(s):

Last Name:

Date of Birth: Day/ Month/ Year

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:

<REGISTER>

Please check your messages

Thank you! You have registered to join Generation Scotland with phone number/email:

Please check your messages to confirm your phone number/email and complete your registration.

If you have any issues or questions, please call on **0131 651 8718** or text us on **07385 413636**.

As a registered volunteer, you may also like to check out our social media channels for our latest updates.

Facebook/Twitter/Instagram