

12-15 Volunteer Information Sheet for Generation Scotland

What is Generation Scotland?

We would like to invite you to take part in a research project, called Generation Scotland. This is a **family study** [FAQ link], where we follow the health and wellbeing of multiple generations of families over time.

Generation Scotland started in 2006 and is run by the University of Edinburgh. We are inviting new volunteers to join.

If you would like to take part, please keep reading. It is important you know why we are doing the research and what is involved. Taking part is voluntary and you can stop taking part at any time without giving a reason.

After you have read the information, we will ask you 2 multiple choice questions. The questions are to make sure we have explained our study properly, they are not a test. They also check that you understand what you are agreeing to.

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.generationscotland.org

Who can take part?

We are inviting volunteers aged 12 and over to join. Volunteers aged 12-15 can take part if they live in Scotland and have a parent or guardian currently taking part in Generation Scotland. Your parent or guardian has already volunteered and they gave us some basic information about you. They have agreed that we can invite you to join too.

What will I be asked to do?

Please read all the volunteer information below. Take time to think about the study and what is involved, before deciding whether to take part. Please ask us any questions you might have. After this, if you want to take part click through to the **online consent form** and complete it. There is no rush to decide.

Once you have completed the online consent, you will be able to continue to the first **questionnaire**. The questionnaire asks about you and your health and wellbeing. You can either start the questionnaire now or return to it later, it takes about 15 minutes to do. After finishing the questionnaire, we will send you a '**spit kit**', to collect a sample of your spit (saliva). We will send it to your chosen address by post and ask you to follow the instructions to provide a sample. Return the sample in the pre-paid envelope provided in the kit.

We will instruct you on how to register an account for our volunteer portal. On the portal you can update your personal details and access future questionnaires.

What else will you collect?

We will follow the health of everyone who agrees to take part by accessing official records. Your NHS health records, for example, can include information about any medicines you may take, vaccinations or if you have any allergies. They also contain information on previous illnesses and visits, such as hospital appointments.

We may access other official records, which can tell us about your health and wellbeing. For example, we may ask the Department of

Education, the Government Census records department, or if younger volunteers begin to work, the Department of Work and Pensions, for information about our volunteers.

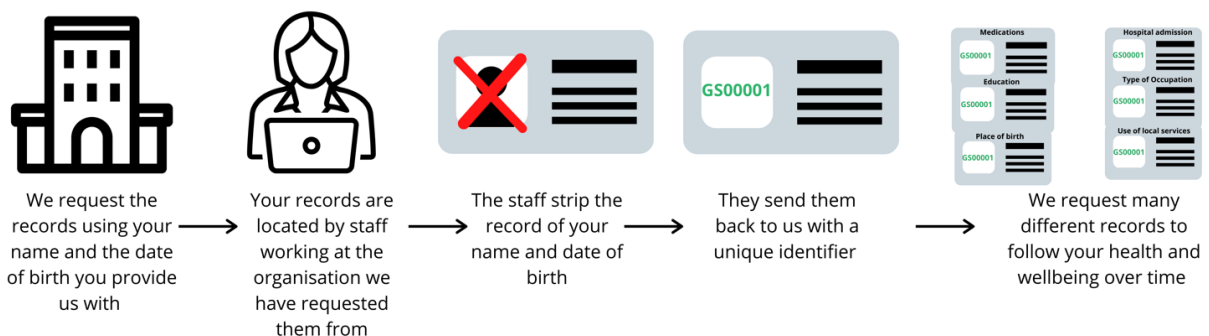
These types of records are called 'administrative records.' It is only now that Generation Scotland has the possibility of linking the information you share with us to these types of records. Because of this, we do not know exactly what information we may receive when we apply to access them. We know that any information that could identify a volunteer would be removed. The Department of Education may send us information about volunteers' grades at school. The Department of Work and Pensions may send us information about volunteers' salary band (for example £20,000-£25,000 band or £35,000-£40,000 band).

The types of administrative records which become available to us can change over time. Therefore, in future, we may access more official records than we have suggested in this information sheet.

When we establish a link to a new type of administrative record we will update our volunteers with what kind of record it is, and tell them about the information it holds. We will be unable to tell individual volunteers what their record says specifically. If we link to a new kind of record and you feel uncomfortable about it, you can get in touch with us to discuss how you want us to handle it.

We access official records through a process called 'data linkage'. Data linkage is a safe and secure way to access official records. We request the records using the personal information you provide us with. The records are then de-identified, meaning your personal information is removed, and saved under a new anonymous identifier. Only approved researchers can access these de-identified records. By using data

linkage we can follow your health and wellbeing over time without you having to do anything extra.



If a doctor or nurse takes a blood sample, there is usually some surplus left over. We may ask the NHS to keep what is left over for our research.

What happens after I join Generation Scotland?

You may be contacted about new studies in the future. This will be based on:

- Information you have given (e.g. questionnaires)
- Information in your official records
- Information from your saliva sample. This will include genetic information. 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

Taking part in other studies is voluntary. You can choose whether or not you would like to take part.

Why take part in Generation Scotland?

Possible Benefits

You will have access to our volunteer-only portal. Research results will be available in e-newsletters and on our website when ready. We'll also post regular updates on social media.

Possible challenges

Volunteering takes time. The first questionnaire will take about 15 minutes to do and we will ask you to do other questionnaires over time.

You can choose whether or not to take part.

Providing a saliva sample is a simple procedure. However, some people might not like it. Some people may be unable to produce a sample.

Producing saliva (around a teaspoon) for the sample kit should take less than 10 minutes.

Just as we ask adults about sensitive topics, we also ask young people about sensitive topics. These questions may include questions about alcohol use, smoking, how you feel about food, your body, gender identity and bullying. You may choose to skip any of these questions, if you do not wish to answer them. You should be given privacy to complete the questionnaire. Your answers will not be seen by your family.

Data and Samples

How will my information be kept safe?

We have taken steps to make sure we keep your information safe and secure. We follow General Data Protection Regulations, often referred to as **GDPR**.

Please answer honestly. We will not share your answers with your parents, or anyone else, other than our approved researchers.

Information and samples collected will be stored securely. We use a password-protected code to hide your personal details. Only approved Generation Scotland team members will be able to identify you. This is only so that we can contact you in the future.

How will my samples and information be stored?

Your personal details will never be kept in the same place as your samples or data.

The Generation Scotland team will always ensure that your samples are well looked after. They will be stored in a secure place at The University of Edinburgh. The exact location may change. In the future, other researchers may ask to use your samples to answer important research questions.

Who will be able to use my information and samples?

Only approved researchers can use your information and samples. This could include researchers from commercial companies or other countries. They must apply to the Generation Scotland team to use your information and samples.

Researchers can only apply to use our data for health-related research, which **benefits the public**. Any data shared will not identify you and will be anonymous.

We **will not** share your information or samples with anyone we have not mentioned, for example we will **not** share your information with:

- School

- Current or future places of work
- Relatives
- Insurance companies

We will let your Doctor know you are taking part in Generation Scotland. This is because we will be requesting your health records. Only the Generation Scotland team will be able to access your personal data.

This study is for research purposes only and is not a pathway to clinical treatment. We provide useful resources and contact details of organisations who support young people and families on some of the topics covered in the study [here](#).

What will happen with Results?

Researchers will publish their results. Researchers will not identify you in any published research.

We will keep you regularly updated about what we find. We will do this through our website, social media and e-newsletters.

Will I be paid?

You will not get paid for taking part. We may work with companies to develop inventions to improve healthcare. You will not be paid for any inventions made using your data.

Has the study 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 wellbeing. The **East of Scotland Research Ethics Committee** reviewed and approved our project.

Will I get information about my genetic results?

We will not return results or provide information to you about your genetics.

Genetic tests on your samples are made for research only. They are not reliable for identifying a disease or condition.

You may be invited to join research studies based on your genetic findings. Researchers normally invite people with and without the genetic finding they are interested in so they can compare different people. This means if you are invited to join a new study you may, or may not, have the genetic finding being researched.

What if I want to stop taking part in Generation Scotland?

It is important to discuss any worries you may have with a member of the study team before joining. You can **contact us** to stop taking part at any time, by phone or email. You do not have to give a reason.

There are two types of withdrawal that can be requested:

- “No further contact”: We would no longer contact you with updates or future study requests. We could still use the information and any health samples you gave. We would still be able to use information from your official records.
- “No further use”: In addition to “no further contact,” we would no longer make your information or samples available for research. We will not be able to remove results from research already started or finished. We would no longer request leftover samples or request your official records. We will make sure your data and samples are no longer available for future research.

Question 1

After reading the information about volunteering to join Generation Scotland, which statements do you think are **TRUE**?

(Tick **all** that you understand to be **true**)

- A. I will provide a saliva sample using a kit sent to my home.
- B. Sometimes, the Generation Scotland team may ask the NHS to keep my left over samples. They will request them from my health provider. Generation Scotland would not have to contact me to do so.
- C. I will have to attend hospital for my saliva sample to be taken.

Question 2

After reading the information above, which statements do you think are **TRUE**?

(tick all that you understand to be **true**)

- A. Generation Scotland may share my data and sample with approved researchers.
- B. Approved researchers abroad, or working for commercial companies, may use my anonymous data and samples.
- C. Volunteers are not given genetic results.
- D. I will be paid to take part in this study.

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.generationscotland.org

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

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 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 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.

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

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.