

## **16+ 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.

If anything is not clear, you can call us on **0131 651 8718** or email us at **[genscot@ed.ac.uk](mailto:genscot@ed.ac.uk)**

You can also find more information on our website

**[www.generationscotland.org](http://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 participating in Generation Scotland who can confirm their capacity and competence to consent.

Volunteers aged 16 and over can take part if they live in Scotland or live in England, Northern Ireland or Wales and are related to a current Generation Scotland volunteer who lives in Scotland.

## **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 20 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 instance, 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.

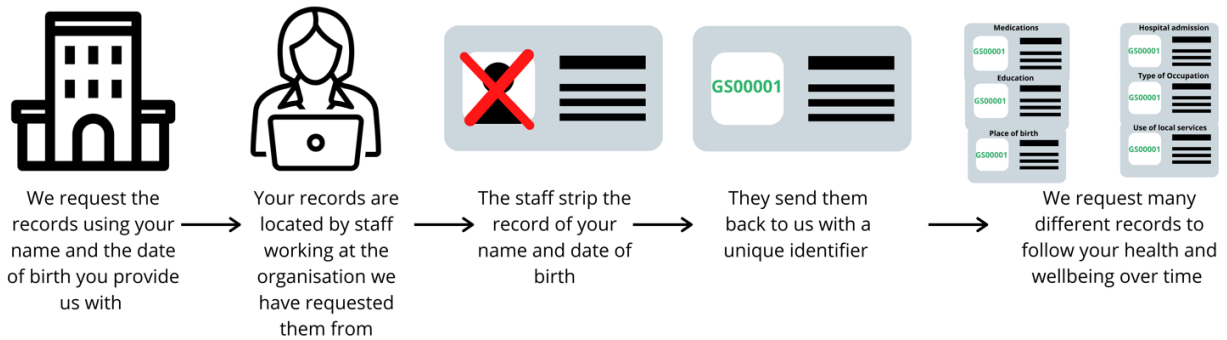
We may access other official records which can tell us about your health and wellbeing. For example, we may ask the Department of Education, the Department of Work and Pensions, or the Government Census records department for information about our volunteers.

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 these 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. 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'd 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 will also post regular updates on social media.

## Possible challenges

Volunteering takes time. The first questionnaire will take about 20 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.

We ask personal questions that relate to your health and the history of health in your family. These questions may include your smoking or alcohol habits, if you have any caring responsibilities, ongoing health conditions, your diet and gender identity. You may choose to skip any of these questions, if you do not wish to answer them.

## 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**.

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'll 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:

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

We will let your GP 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 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.

## **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](http://www.generationscotland.org)



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## 16+ 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 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.