



Traveller Genes

We'd like to invite you to join Traveller Genes, a research study looking at the genetics and health of volunteers who have at least **two grandparents** who are or were **Travellers** (including **Scottish Travellers, Irish Travellers, Romanichal or Romany, or Welsh Kale**). It's been created in response to a request from the Traveller community. We're trying to take careful account of the views and priorities of Travellers in the design and conduct of this research.

Traveller Genes aims to:

- Identify the genetic origins and relationships of the Scottish Travellers and their subgroups (e.g. Highland Travellers)
- Work out how Scottish Travellers relate to each other, to the Irish Travellers and English Gypsies, as well as the "settled" Scottish and neighbouring populations
- Better understand overall patterns of health and disease, and their genetic risk factors, in the Traveller community.

If you choose to take part, you'll be invited to fill in an online questionnaire and give a saliva sample, using a kit that will be posted to you. With consent and approvals, records held by the NHS in Scotland will be linked and used by Traveller Genes to follow the health status of participants. Any discoveries made in the study about the genetic information of individuals will not be reported to the volunteers.

Before deciding if you'd like to take part, it's important you understand why we are doing the research and what it will involve. Please take time to read the information in this leaflet carefully, before making your

decision. Thank you for taking your time to consider taking part in Traveller Genes.

If anything isn't clear, or if you'd like further information, you can call us on **0131 651 8557** or email us at travellergenesis@ed.ac.uk. You can also find more information on our website www.ed.ac.uk/travellergenesis



Complete online consent



Fill in online questionnaire



Send saliva sample by post



Involvement complete, until possible recontact!

What is the aim of the study?

The study is run by a team based at The University of Edinburgh, led by Professor Jim Wilson.

The Scottish Travellers, Irish Travellers, and Romanichal or Romany populations of the British Isles and Ireland are traditionally nomadic communities. They were socially isolated from the settled populations until recently. Some genetic studies have been carried out, but Scottish Travellers in particular have not yet been studied. Traveller Genes will use genetic analysis to provide information on the origins of these communities and their relationships with each other and with the settled populations among whom they live, and others worldwide. We aim to recruit around 200-400 people.

The chance of developing diseases, such as heart disease, lung disease and some cancers, is affected by your genes. Genes are passed through the family and are 'written' in your DNA. Traveller Genes will also look into whether Traveller populations have different patterns of ill health or carry different genetic risk factors to the settled populations of the British Isles. We'll use current and historical records, along with DNA from your saliva

sample, to create family trees of participants. This allows research into the genetic history of Travellers, across different families and kinship groups.

Am I eligible?

You **can** take part if you:

- Are aged 16 or over
- Have access to the internet, to complete the questionnaire
- Have at least two grandparents who are or were Travellers



You **can't** take part if you:

- Are under the age of 16
- Can't access the internet to complete the online questionnaire
- Don't have at least two grandparents who are/were Travellers

If you're not sure about any of these criteria, please don't hesitate to ask us about them.

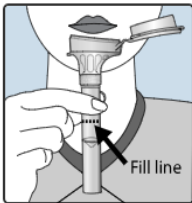
What would I be asked to do?

If you'd like to join, the study would involve:

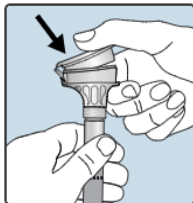
- Signing the consent form. By clicking the link in the email we send following registration, you will be taken to the consent form. Before deciding, you can ask us further questions by calling us on **0131 651 8557** or emailing travellergenes@ed.ac.uk
- Completing a short online questionnaire, which you will be taken to once consent has been signed. You can either start the

questionnaire immediately or return to it later. The questionnaire will ask for details about your ancestry and health. If you haven't completed the questionnaire, we'll send you a reminder email after approximately 2 weeks and 4 weeks have passed.

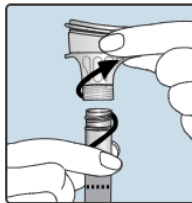
- Providing a saliva (spit) sample. After questionnaire completion, you'll be sent a saliva kit, by post, to your home or a nominated contact. You'll be asked to follow the instructions (similar to those below) and provide a saliva sample. The sample should then be returned to the address provided. Return postage is prepaid for volunteers in the UK. If we don't get a sample, we'll email you a reminder after about 2 and 4 weeks.



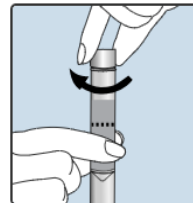
1. Spit until the saliva (not bubble) reaches the fill line.



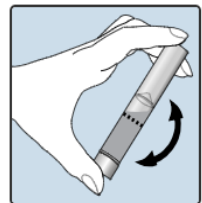
2. Close lid tightly by pushing down hand on the funnel lid until you hear a loud click.



3. Hold the tube upright. Unscrew the funnel from the tube.



4. Use the small cap to close the tube tightly.



5. Shake the capped tube for 5 seconds. Discard funnel.

Your genetic material (DNA) will be taken from your saliva and studied by researchers. This may include Whole Genome Sequencing, where we'd read and study all 6 billion letters of your DNA. This means we can look at whether any changes in the DNA tell us more about the genetic history of the Travellers. It may also help tell us if any genes are important in health or disease.

When consenting, we will ask you to agree to recontact, so you may be invited to take part in future studies. Details of these studies will be given at the time of recontact. You don't have to take part in any future study you are invited to – this will be your choice when contacted.

How will I benefit from the study?

The main benefit is the chance to help historical and medical research. You'll be supporting the researchers, who will use your data to understand the genetic makeup of the British Isles. This will include the origins of Travellers and also whether Travellers have particular genetic risks or patterns of disease.



Once the initial analyses are complete, we'll feedback the general results of the research to the community. It's unlikely we'll have any results available to publish for a considerable time. The data will continue to be used in future medical and genetic research projects, all approved by a Research Ethics Committee.

What are the possible disadvantages of taking part?

Completing the questionnaire will take about 15 minutes. Producing the saliva required (a teaspoon) for the kit and posting this back to us can also take some time.



How will my data be kept secure?

We've taken steps to ensure your **privacy is protected**:

- Your registration of interest form, consent and questionnaire will include details that can identify you. These forms will be stored in a secure location and kept separate from the study data.

- Study data and DNA from your saliva sample will be carefully stored indefinitely in secure buildings, using a unique anonymous identification code.
- All study data will be stored in a password-protected study database. The data will be linked to your unique identification code.
- Your saliva sample will be processed and the DNA stored in a secure lab with your unique identification code. Your personal details will never be stored with the samples or data.



Who will be able to use my data and sample?

Your information and samples will only be used by researchers who have relevant scientific and ethical approval for research. This could include researchers working in other countries or with commercial companies who are looking for new treatments or lab tests.

We plan to look for patterns of ill health in people who take part in the study. The Public Health Scotland Division (PHS) of NHS Scotland records data including drug prescriptions, hospital admissions, GP records and lab tests. During consent, we'll ask you to agree to details of your past and future health being shared with us.

We'll send PHS your name, address and date of birth, in confidence, so they can find your records for us. We'll ask your permission for trained Traveller Genes team members to view these records, which could be useful for research.

We'll also use records, stored at Register House and online, to create family trees of yourself and others taking part. It is important in genetic analysis to know who is related, so that we can track genes in families. All information is treated confidentially.

Data and samples won't be released to any researcher in an identifying way. We won't provide your sample to security services or lawyers, unless required to do so by court order.

Where can I find out more about how my information is used?

You can find out more about how we use your information

- On the study website at www.ed.ac.uk/travellergenes/privacynotice
- By asking one of the research team using the contact details at the end of this information sheet
- By sending an email to travellergenes@ed.ac.uk
- By contacting the University's Data Protection Officer via email at dpo@ed.ac.uk



Can I see the results from research projects?

Researchers publish their results to share knowledge, so people can benefit from it. We'll regularly update our website, www.ed.ac.uk/travellergenes, with our research. It won't be possible to identify individuals in any of the published research.



What if my data or sample creates an invention?

You're providing your sample as a gift. You won't receive any payment for your contribution. Traveller Genes won't sell your data or sample.

Samples and data may be made available to other research institutions, in the public and private sector, in the UK and overseas, to help researchers make a new treatment, medical test or other product. If such an

invention is created from research on your data or sample, you won't receive any compensation or payment.

Is the study approved?

Our research has been reviewed by an independent group of people, called a Research Ethics Committee. They're here to protect your safety, rights, wellbeing and dignity. This project was reviewed and given a favourable opinion by the London – London Bridge Research Ethics Committee.

Do I have to take part?

No, joining the study is entirely voluntary. Your choice of whether to take part or not won't impact on the level of care you receive from the NHS, now or in future.

How do I withdraw, if I would like to?

It's important, before you join the study, that you discuss any concerns with a member of the study team. Our research is more valuable if few people choose to withdraw from the study.

However, you can withdraw at any time without giving a reason. This can be done by calling us on **0131 651 8557** or emailing travellergen@ed.ac.uk. You can also write to us at the address at the end of this information sheet.

There are two types of withdrawal that can be requested:

- **“No further contact”**: This means we'd no longer contact you with study updates or requests to join future studies. However, we'd

still have permission from you to use the information and sample you previously provided. We'd also still be able to receive information from your health records. We'll also follow this path if you lose capacity to consent.

- **“No further use”:** In addition to “no further contact,” we'd no longer make your data or samples available for research. Please note, we won't be able to remove results from research already performed or currently being performed. We will ensure that your data and samples are no longer available for future research.

How do I contact you?

If you have any questions, concerns or complaints about anything to do with our study, you can contact us using the methods below:

By Phone: **0131 651 8557** Mon – Fri 8.00 – 16.00
(answerphone outside working hours)

By Email: travellergen@ed.ac.uk

Alternatively, you could write to us at:

Traveller Genes,
Doorway 1, Usher Institute
The University of Edinburgh
Teviot Place, Edinburgh, EH8 9AG
Scotland, UK



Independent advisor/complaints contacts

If you would like to speak to someone about the study who is not part of the research team, please contact Prof. Gianpiero Cavalleri on 00 353 1 402 2146 or email gcavalleri@rcsi.ie

If, after discussing any issues with the research team, you wish to make a formal complaint about the study, please contact the University of Edinburgh's Research Governance team via email at:

researchgovernance@ed.ac.uk