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## VIKING GENES PRIVACY NOTICE

### **In this Privacy Notice we:**

- 1) Summarise how we use your information
- 2) Provide detail on our legal basis for using this information
- 3) Provide general privacy notice information for all
- 4) Provide privacy notice information specific to researchers
- 5) Provide privacy notice information specific to study participants

## 1) HOW WE USE YOUR INFORMATION

This privacy notice tells you what to expect when VIKING II, ORCADES (also known as Orkney Complex Disease Study), or VIKING (also known as 'Viking Health Study – Shetland'), collectively "Viking Genes", collects your personal information.

Viking Genes is a cohort study, run by The University of Edinburgh. The University is the 'data controller' as defined in the Data Protection Act. Viking Genes complies with the requirements of the General Data Protection Regulations (GDPR) and the Data Protection Act (2018) with regard to the collection, processing, storage and disclosure of personal information.

Viking Genes gathers information about participants from questionnaires, samples and other sources such as health records, family history data, and national registers. Viking Genes processes these data to make sure they are as accurate as possible, and to remove the risk that any person may be identified from the data. Viking Genes then shares these data with qualified researchers, in order to conduct research aiming to improve the public good, for example, by increasing scientific knowledge.

This document explains how we will use any data that you share with us. We are legally required to tell you how we will use this information and give you the opportunity to tell us not to use your information in that way.

It applies to information we collect when you:

- Visit our website
- Post information on social media
- Phone or email us

It applies when researchers:

- Complete a data transfer agreement, material transfer agreement, or confidentiality agreement
- Submit a manuscript for review

And when participants:

- Complete questionnaires via our website
- Return completed questionnaires, consent forms, reply slips or any other written information

It also applies to the way we handle, process and store your information when:

- Sending out mail and email
- Storing questionnaires and consent forms
- Collecting data from routine official records (NHS and other health records; records of births, marriages and deaths kept at the General Register Office for Scotland)
- Providing research data for use in scientific research

We also provide participants with further information on privacy, confidentiality and anonymity via post and email when we send newsletters or ask you to take part in questionnaires.

## 2) OUR LEGAL BASIS

### Who controls the use of our data

The use of the data directly collected by Viking Genes is controlled by The University of Edinburgh. The Data Controller at The University of Edinburgh can be contacted at:

Data Protection Officer  
Governance and Strategic Planning  
The University of Edinburgh  
Old College  
Edinburgh  
EH8 9YL  
Scotland

### Complaints or queries

Viking Genes aims to meet the highest standards when collecting and using personal information. We encourage people to tell us if they think that our collection or use of information is unfair, misleading or inappropriate. We also welcome any suggestions for improving the way we handle your personal details.

This privacy notice is intended to be brief and clear, and does not cover every single way we handle your personal details. However, we are happy to provide further information on request.

If you would like to complain about our handling of your data, you can contact the University's Data Protection Officer via email at [dpo@ed.ac.uk](mailto:dpo@ed.ac.uk)

### Our legal basis:

The purpose of Viking Genes is to conduct scientific research that aims to improve the public good. This is part of the wider purpose of The

University of Edinburgh to conduct research aiming to improve scientific understanding.

Our legal basis for using your information, under GDPR and the Data Protection Act 2018, is:

1. Performance of a task carried out in the public interest (Article 6(1)(e) in the GDPR); and, where sensitive personal information is involved:
2. Scientific or historical research purposes or statistical purposes (Article 9(2)(j) in accordance with Article 89(1)).

The GDPR defines "sensitive personal information" as "information that reveals a person's racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership; and the processing of genetic data or biometric data for the purpose of uniquely identifying a person; data concerning health or data concerning sex life or sexual orientation."

This legal basis within GDPR and the Data Protection Act 2018 is separate to, and in addition to, our seeking consent to take part in the research process, which we use to help ensure our research is ethical and complies with other applicable laws.

When you enter your information in a form, we specify the purpose and future use of this information. By submitting information to a form, you consent for your details to be used according to the purposes stated within each form. Our legal basis for using your information in this way is consent.

An example of this would be provision of your email address, to be added to our mailing list (which will be used to send you newsletters and information). As this information is provided on the basis of consent, you are free to withdraw your consent for such use of your information at any time.

We may disclose your personal information to third parties if we are under a duty to disclose or share your personal data in order to comply with any legal obligation, or in order to enforce or apply our terms of use and other agreements; or to protect the rights, property, or safety of Viking Genes, or others.

### **3) PRIVACY NOTICE INFORMATION FOR ALL**

#### **Visitors to our website**

When someone visits our website we collect standard internet log information and details of visitor behaviour patterns. We do this to find out things, such as the number of visitors to various parts of the site and to help us monitor and improve our site. We collect this information in a way which does not identify anyone. We do not make any attempt to find out the identities of those visiting our website. We will not associate any data gathered from this site with any personally identifying information, from any source. If we do want to collect personally identifiable information through our website, we will be up front about this. We will make it clear when we collect personal information and will explain what we intend to do with it. We do not generally provide any personal information about users of our website to third parties or other users.

This notice is separate to, but supported by, The University of Edinburgh's website privacy policy, available at <https://www.ed.ac.uk/about/website/privacy>

#### **Posting information on social media**

Viking Genes maintains a number of social media presences, including on Facebook, Twitter and YouTube. Users of these social media should be aware that any information posted is covered by the terms and conditions of the respective site and is in the public domain.

Please be aware that you have a responsibility to ensure that any information you post on our social media sites is within the bounds of the law.

### **Communications (including newsletters)**

We are keen to communicate our activities, latest news and opportunities for further research with stakeholders and supporters, including participants. We do this by providing information through a range of online and offline channels including publications, events, press releases, social media and email.

In order to do this we have a database that contains personal data collected by Viking Genes during the course of our relationship with you. We aim to keep your data up to date and welcome any updates to your details or corrections to any inaccuracies you may wish to provide.

Your information is stored on our contact management system, held securely by The University of Edinburgh. The data is password-protected and accessible only to The University of Edinburgh employees.

Each newsletter you receive from us will give you the opportunity to unsubscribe from future newsletters. To unsubscribe you can reply to an email newsletter with the word 'UNSUBSCRIBE' in the subject line. You can also let us know using the contact details below in **"How to contact us"**

### **Accessing personal information**

As an individual, you have a right under the GDPR to update or amend the personal information we hold about you. You can ask us to remove your personal information from our records and to obtain information from us, including a description of the personal data that we hold on you. For more information about this, please contact us.

Viking Genes aims to be as open as it can be in terms of giving people access to their personal information. Individuals can find out if we hold any personal information by making a 'subject access request' under the Data Protection Act 2018. If you are a participant, we will:

- give you a description of it;
- tell you why we are holding it;
- tell you who it could be disclosed to; and
- let you have a copy of the information in an intelligible form

However, we will not provide you with a copy of the raw genetic data derived from your DNA. This is because we have to stick closely to the detailed description of our research plans as approved by the University and NHS regulators. This exemption is compliant with the GDPR.

To make a request to us for any personal information we may hold, you need to put the request in writing to the address provided below and on our website.

If you agree, we will try to deal with your request informally, for example by providing you with the specific information you need over the telephone or by email. If we do hold information about you, you can ask us to correct any mistakes.

### **Links to other websites**

This privacy notice does not cover the links on our website to other sites. We encourage you to read the privacy statement on any other website you visit.

### **How to contact us**

If you want to request information about our privacy policy you can contact us via the details on our website. Further information is also available in The University of Edinburgh's Information Security Policy, available at [https://www.ed.ac.uk/files/atoms/files/uoee\\_informationsecuritypolicy\\_v2.0\\_approved.pdf](https://www.ed.ac.uk/files/atoms/files/uoee_informationsecuritypolicy_v2.0_approved.pdf)

You can call us on 0131 651 8557, email [viking@ed.ac.uk](mailto:viking@ed.ac.uk) or write to:

Viking Genes, MRC Human Genetics Unit, MRC Institute of Genetics & Cancer, The University of Edinburgh, Western General Hospital, Crewe Road South, Edinburgh, EH4 2XU, Scotland.

#### **4) INFORMATION FOR RESEARCHERS ONLY**

##### **Collaboration proposal form and supporting documents**

This data includes the name and contact details of the Principal Applicant, and those of any co-applicants and any other data users on the proposal and supporting documents. We will use this data so we can communicate with you about your proposal. We may also collect your personal details on a number of supporting documents related to your proposal. These include: data access agreements, data transfer agreements, material transfer agreements, confidentiality agreements or data user responsibilities agreements.

We may also collect your personal details when you submit a manuscript to us for review.

We will never sell your personal information to other organisations. The accuracy of your information is important to us. If you believe any information we hold concerning you is out of date, please let us know.

## **5) INFORMATION FOR VIKING GENES PARTICIPANTS ONLY**

### **Our commitment to you**

Taking part in the project is voluntary and you are free to withdraw at any time without giving a reason.

You will not be identified from the research – researchers do not see your name with your information – they just see your barcode ID number. Every internal and external research project is checked to make sure it meets the highest scientific and ethical standards. The VIKING team at The University of Edinburgh, and all the researchers we work with, are bound to keep your information confidential.

We do not do research with the aim of commercial gain - all our research aims to benefit society. This could include collaborations with researchers working in other countries or with commercial companies who are looking for new treatments or lab tests.

### **Changing your mind**

If you wish to change the way you participate – or stop participating – in Viking Genes you can do so at any time. Please contact us to let us know.

If you want to leave the study and stop us using your data we can do this. Please note that it is not possible for us to stop using all of your information, if it is already being used by researchers. No new research will be started using your data. We will keep a simple record about you on our database so that we know **not** to contact you.

### **Phoning or emailing us**

When you phone or email us we will verify your identity and ensure that you are a study participant before proceeding. Information that you give us will be recorded in our contact management system. We will also

record relevant details (such as date or time) of the phone call or email message.

The University's third party email provider is Microsoft (Outlook). Please be aware that you have a responsibility to ensure that any email you send to us is within the bounds of the law.

### **Completing questionnaires via our website**

When you login to the questionnaire portal of our website we will collect standard internet login information and details of visitor behaviour patterns to help us understand how people are accessing different parts of the questionnaire. We will also use this information to decide if you have completed your questionnaire or not, and may then contact you to remind you to complete your questionnaire if you have not already done so.

If we want to collect personally identifiable information through our website, we will be up front about this. For example, at the start of the questionnaire we will make it clear when we collect personal information such as your date of birth and will explain what we intend to do with it.

When completing your questionnaire online, all information you provide is confidential. Your research data and personal details are kept separately. No researcher will see your name linked to your research data.

Online questionnaires are administered on The University of Edinburgh-owned computer systems.

## **Returning completed questionnaires, consent forms, reply slips or other written information**

When you return an item to us in writing (for example a questionnaire, consent form, reply slip or written letter) we will treat this information as confidential. Your personal details will be kept separately from your research data. We will not pass your personal details to third parties without your consent except under the circumstances described below.

## **How we will use your personal details**

We will keep your personal details confidential, and separate from your research data. Your personal details will not be shared with third parties, except for certain service providers working on our behalf.

These third parties include:

- The Health Informatics Centre (for printing and collating large mailings). The Health Informatics Centre (HIC) is a University of Dundee research support unit within the Tayside Medical Science Centre (TASC) and offers a Trusted Research Environment for research that uses sensitive data.

We will only share your personal details with these third parties under strict conditions set out in a legally binding data processing agreement. This offers assurances about the use, access and security of any personal data disclosed and does not allow any onward disclosure or sales of personal data by the third party.

We also use Royal Mail for posting questionnaires and sample kits, invitations to take part and other correspondence.

Some research projects need information based on location, such as where you live, or where you were born etc. We do this in a way where the information about you that is used in our research (such as the

information you give in questionnaires) cannot be linked back to your address.

## **How we will use your research data**

We will only collect your data with permission, for example by asking you to complete a questionnaire. Once we have collected data, it will be processed for research use. It will be stored securely and confidentially. We will de-identify the research data, so you cannot be identified from it. We will then provide this information to qualified researchers on request and only under strict conditions.

For general information about how we use your data, please go to [edin.ac/privacy-research](http://edin.ac/privacy-research)

## **Social media**

Viking Genes will not use your personal information on social media for medical research without your explicit approval. We won't approach you to do so without first having received an ethical opinion from the NHS Research Ethics panel to which we are responsible and the Data Access Committee.

Outside of this, social media will only be used as a communication tool between you and us. We may store your Facebook URL, Facebook email address or Twitter username so that we may continue to communicate with you. This administrative data will be stored securely in our contact management database, along with your other contact details that you have provided to us.

## **Collecting data from routine official records**

A great deal of information is collected and stored about all of us in our official records. This information gives a detailed picture of many aspects

of our life. Viking Genes researchers use this information alongside the information we collected about you (for example, in study questionnaires).

With your consent, Viking Genes will identify and get a copy of parts of your official records, including those held by the NHS. We call this way of information collection 'data linkage'.

We will not provide the organisations (such as the NHS) who keep your records with any of the information you have given Viking Genes. Collection of this information by Viking Genes will not affect the services you receive from government departments in any way. To make sure we accurately identify your records, we will use your NHS community health index number to make a link to the information in your routine health records.

### **Who we share data with**

Viking Genes operates as a scientific resource for the legitimate research community. Researchers working at Universities, in government departments, at charities or other organisations (including commercial companies) across the world may apply to access research data. Each application is assessed by our Data Access Committee, who decide whether the researcher is legitimate, if the data requested is needed to conduct the research, and if the research project can be conducted in line with the commitments we have made to participants. We only share data in a way that protects your confidentiality.

You were already told about the long-term (potentially lifetime) use (and re-use) and retention of your personal information in connection with the specific research study in which you are a participant.

### **About this Privacy Notice**

We reserve the right to make changes to this Privacy Notice.

The most recent modification was made on 22<sup>nd</sup> March 2022.