VIKING Genes

Participant Information Sheet

Return of Results – Next of Kin

New permissions have allowed us to provide the next of kin of participants in our Viking Genes studies with the chance to have some genetic results returned, if they would be of benefit.

We'll only inform you about these results if we find any that might have been relevant to the health of your next of kin and therefore potentially their family, during our research.

The following information will tell you about why we might want to return results, and what it could mean for their family.

If you have any questions after reading this information sheet, you can call us on **0131 651 8557** or email us at viking@ed.ac.uk

What is genetic research?

Genes are made up of DNA, which is the material found in humans and all other living things. We share more than 99% of our DNA with all other people. However, the small differences help define each person's features and chances of disease.

Genetic research is the study of genes and how these small differences in genes can affect people's health and well-being.

What is an 'actionable' genetic result?

Sometimes, we may find 'actionable' genetic results that we'll want to share. 'Actionable' genetic results are gene changes a person may have that are linked to a treatable condition or disease, for example an inherited predisposition to heart disease or cancer. We'd like to tell you as next of kin about some of these changes, if we find them.

These gene changes are uncommon. We expect that about one or two in every hundred people will have them. We'll only let you know about these results about your next of kin if you agree for us to do so. You can change your mind about this at any time.

Medical professionals keep lists of genes in which there could be changes that we can let volunteers, or their next of kin, know about. This list will change over time, as science gets better at predicting which gene changes cause disease. We're only offering to return a limited set of genetic findings, but we will try to continue to return results for as long as possible.

Why do you want to return these results?

If we find information as part of our research that could improve the health of the family of one of our volunteers, we feel you as next of kin should be given the chance to know about it. Once you and your doctors are aware of it, steps can be taken to prevent or reduce the impact of the gene on the future health of the family.

When will I receive feedback?

We have begun the feedback of results, and if an actionable finding is made, we would aim to contact you by letter as soon as possible, if you consent as next of kin. You will most likely not get any

feedback, because only those with 'actionable' genetic results will hear from us.

What happens if there is an 'actionable' result?

We will discuss any potentially important results with the NHS Clinical Genetics Service in Aberdeen. An NHS genetics expert will assess what it means for the family of your next of kin, before we would send you a letter.

What could this mean for the family?

If you have an 'actionable' result returned, the letter will include contact details for the NHS clinical genetics team. If you get in touch with them, the risk to the family of your next of kin will be explained by an NHS genetics expert. They'll support, advise and answer any questions you may have. If your next of kin carried an actionable finding, it does not mean their children will definitely carry this genetic variant.

NHS experts on genetic findings in families would confidentially discuss the benefits and risks of genetic testing in the NHS. They will also advise you on the next steps family members can take, including treatment and prevention of the condition, where necessary.

What are the risks to having results returned?

You may become anxious if you learn that your next of kin's family may have an increased chance of disease, due to their genetics. It's natural to be concerned about a positive result and this is why you would be able to receive advice from trained NHS staff. You can be assured that we won't inform you of any finding that can't have actions taken to resolve or reduce its impact.

Has this study been 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 amendment was reviewed and given a favourable opinion by the South East Scotland Research Ethics Committee of NHS Lothian.

Where can I find more information?

You can find out further information about return of results on our website:

www.ed.ac.uk/viking/volunteer-for-viking/faqs/return-of-results

You can also read more about how we protect the privacy of our volunteers here:

https://www.ed.ac.uk/viking/privacy-notice

How do I contact you?

You can contact us if you have any questions, concerns or complaints about anything to do with our study:

By Phone: **0131 651 8557** Mon – Fri 9.00 – 17.00

By Email: viking@ed.ac.uk

Or, you can write to us at:

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

Independent Genetic Advisor

Prof. Zosia Miedzybrodzka has agreed to be the independent genetic advisor of the study. Zosia will be able to answer any specific questions about genetics in VIKING Genes that you may have. You can contact Zosia using her details below:

Email: zosia@abdn.ac.uk

Prof. Zosia Miedzybrodzka
Medical Genetics Group,
University of Aberdeen,
Polwarth Building,
Aberdeen, AB25 2ZD, Scotland

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. Sarah Wild on 0131 651 1630 or email sarah.wild@ed.ac.uk

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