Viking Genes

[Viking Genes Homepage]

Welcome to your Winter newsletter!

Happy New Year from the Viking Genes team!

Welcome to a new edition of our newsletter, we're excited to share some important milestones with you. We begin with our latest research paper — the first to directly benefit volunteers in the Viking Genes *Hebrides* study — and spotlight four inspiring volunteer stories that show the real-world impact of our return-of-results programme. You'll also find encouraging news about the unanimous support for the Shetland Community Screening Project, along with an introduction to one of the most promising areas in genomic medicine: pharmacogenetics. To round things off, we bring you an update on the Viking Genes Shetland fundraising campaign and announce two new funds dedicated to the Hebrides and Orkney communities.

Read on to find out more.

The landscape of hereditary haemochromatosis risk and diagnosis across the British Isles and Ireland

Research identifies Northwest Irish and Outer Hebridean populations at highest risk of carrying harmful haemochromatosis variants, leading to calls for screening

Highest frequency in Celtic-speaking populations has ancient origin

Hereditary haemochromatosis (HH) is one of the most common genetic conditions in people of European ancestry and leads to a build-up of iron in the body, which can poison the organs, causing liver cancer, cirrhosis and arthritis, among other things. The main cause is the major genetic risk variant, the scientific name for which is C282Y. The highest global frequencies of this variant are found in the formerly Celtic-speaking populations in Ireland and Scotland, hence haemochromatosis is sometimes called the “Celtic Curse”.

Ancient DNA showed that an Early Bronze Age individual from Rathlin, an island off the coast of Northern Ireland, was a C282Y carrier. This means the variant existed at least 4,000 years ago, and in a geographic region where it is found to be common today. It has been speculated that this may relate to an advantage when a low iron diet predominated, although given such a diet was widespread, it may be more likely that the high frequency is simply due to people not moving around much and many people descending from the same ancestors in this area over thousands of years.

Prof Flett Wilson said: "That skeleton was a carrier of haemochromatosis. This means, it has been in the Northern Ireland and Scotland area at least 4,000 years. I think that everyone in Scotland and in Ireland and England who has this variant, they all come down from a person 5,000 or more years ago and everyone is a descendant of this founder individual."

A research project, led by Professor Jim Flett Wilson of the University of Edinburgh and funded by the charity Haemochromatosis UK, has provided scientific evidence of the priority target areas where the need for population screening is highest.

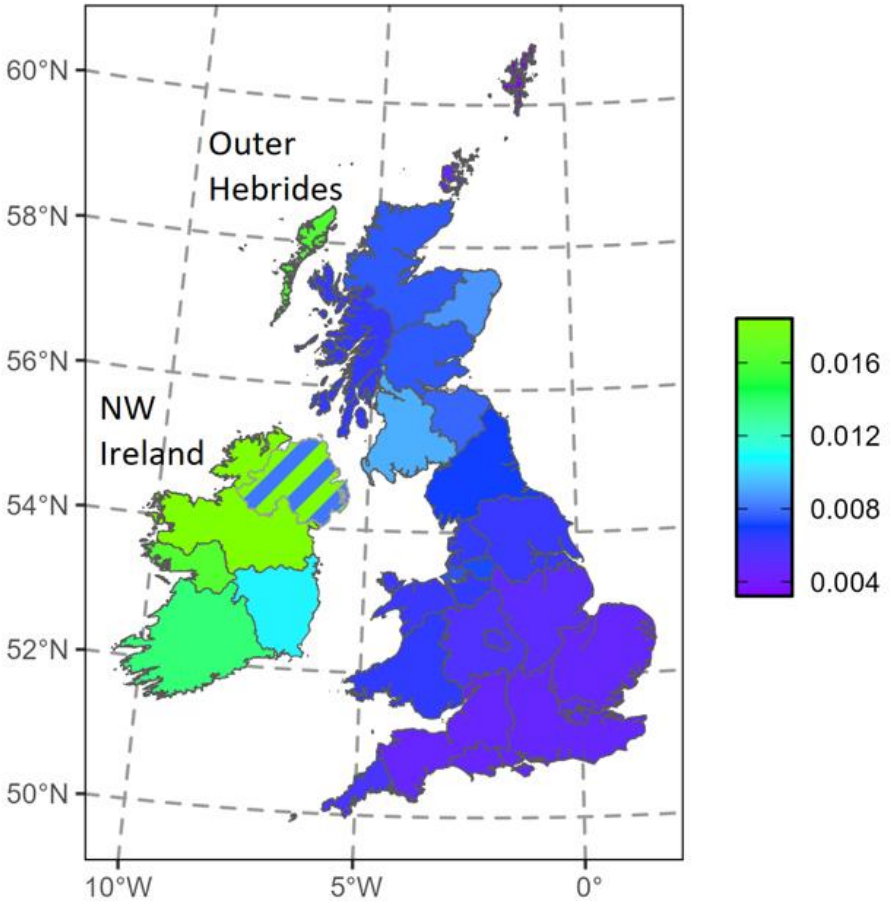
The University of Edinburgh’s Viking Genes researchers and colleagues in Dublin investigated the frequency of genetic haemochromatosis within Scottish island populations, using Viking Genes data, and also data from research volunteers across the rest of Britain and Ireland.

There is considerable benefit in identifying the genetic risk for haemochromatosis, since the symptoms of the condition evolve over decades, and the opportunity to intervene and prevent disease is both simple and effective, primarily through regular blood donation. If left untreated, the progression towards iron overload can lead to a range of symptoms from changes in skin colour, chronic fatigue, joint and bone pain to liver fibrosis, cirrhosis, and cancer. The risk of haemochromatosis is higher in males than females, due at least in part to monthly blood loss in pre-menopausal women. Men with haemochromatosis are eight times more likely to develop liver cancer.

The heightened risk of haemochromatosis discovered in people of Northwest Irish and Hebridean ancestry identifies priority areas where population screening would be of most benefit.

The team analysed data from over 400,000 individuals to determine the genetic risk across 29 regions of the British Isles and Ireland for the major risk variant, HFE p.C282Y, and created a frequency map.

Professor Flett Wilson said: "The map will be incredibly useful. If you are trying to run a centralised healthcare system like the NHS, if you don’t know where your patient groups are, it is very hard to allocate resources to the right geographic area."



Map of the landscape of hereditary haemochromatosis risk across the UK and Ireland. Areas with a higher frequency of the disease-causing C282Y genetic variant are indicated in green. Hatching is used to represent two communities in Northern Ireland, each with different risks.

Northwest Irish and Outer Hebrideans are at the highest risk (1/54 – 1/62 carry the major risk variant), higher than Northern Ireland (overall 1/71). Mainland Scots are also at increased risk (1/117), declining to 1/212 in Southern England. The Northern Isles of Scotland have low frequencies, Orkney (1/209) being similar to southern England, while Shetland (1/309) is the lowest of all the British Isles and Ireland.

The team also assessed the prevalence of a diagnosis of haemochromatosis in >63 million people in NHS England and identified 70,365 cases. White Irish individuals have the highest prevalence (3.7x white British). Among white British, prevalence varied 11-fold from 1/1972 in parts of Kent to 1/177 in Liverpool. Discrepancies between genetic risks and prevalences for Birmingham, Cumbria, Northumberland and Durham suggest under-diagnosis in these regions. It can be speculated that the high prevalence and high genetic risk the researchers found in Merseyside may originate in part from the historically large Irish diaspora in and around Liverpool.

Analysis of grandparental origins within the Outer Hebrides shows that the C282Y variant is found at frequencies over 12% all the way from Barra and Uist in the south to Lewis in the north. It was noted that the estimated frequency is also very high in the Isle of Skye (15%), using the small sample

available in Viking Genes. Further study is thus required to assess the degree to which Sgiathanachs (people from the Isle of Skye) would also benefit from screening.

Professor Flett Wilson added: *"I strongly believe there should be screening, so I saw the chance to do a study to ask where in England, Scotland, Ireland and Wales it's the most common, where are the hot-spots, are there any cold spots. Before this project it was very vague, so we have looked in 29 regions and created this map, which provides good evidence for where screening would find the most people suffering iron overload."*

Torcuil Crichton, the **Labour MP for Na h-Eileanan an Iar (the Western Isles)**, has haemochromatosis and supports Professor Flett Wilson's call for community screening for the haemochromatosis genetic variants in the Western Isles. He has personally championed the cause in Parliament and secured a Westminster debate on 25 June 2025. Click here to read our web piece on the debate, with link to the full text of the debate on Hansard.

The **MP** said: "Everyone in the Western Isles should be screened for too much iron in their blood but also offered DNA tests to show what inherited conditions they might carry. This would be revolutionary. It would save money for the NHS in the short term and the long-term. More importantly, it would save lives and put us two decades ahead of the rest of the country in preventative medicine."

Read our research summary with link to the paper*

Haemochromatosis Volunteer Stories

Viking Genes spoke to John, Alan, Kenneth, and Mairi, to find out what happened after they received the letter from Prof Jim Flett Wilson, reporting that we had discovered actionable variants in the haemochromatosis (HFE) gene in their DNA samples.

"In the Outer Hebrides, it's predicted that nearly 500 people in our small population will carry the haemochromatosis gene variants. Screening the community is vital.
A nurse recently told me she didn't understand how I was still functioning;
it's something I've lived with unknowingly for years."
- **John** (left)

"I've always been fit and active, and I've never been in hospital since I was a kid. But for the last couple of years, I've been getting up to saying, oh, my knees are painful, my ankles are sore, and they say, oh, its arthritis. And my health was going down and down and down, and I couldn't do the things that I did five years ago. I was getting worried because you come up for retirement. Do you want to enjoy retirement? I've got tons of stuff to do. So, I think I'm really, really lucky that I found out now. I'm now spreading the news; I tell everyone about it: "get yourself checked out!"

- **Alan** (2nd left)

"I think screening for haemochromatosis in the Outer Hebrides is a sensible idea. It's prevalent here, and within NHS Western Isles, we even have a dedicated tab for managing it in our internal system. Yet, it's not well known in the community. Screening is simple, inexpensive, and could prevent serious complications down the line. Given the geography of our islands, early detection could save people from costly travel and missed work. It would empower GPs to intervene early and manage the condition proactively."

- **Kenneth** (2nd right)

"I want to emphasise that I pursued these tests and treatments solely because of the Viking Genes genetic testing. Without it, I might have gone years without knowing I was at risk. I'm thankful to the team for identifying this condition while I was still asymptomatic. Their work allowed me to take action early and avoid future complications."

- **Mairi** (right)

Read their powerful stories in full *

Shetland Community Screening Project: A New Era for Preventative Health

Last May, the Mareel theatre in Lerwick became the stage for a new chapter in Shetland's public health story. Professor Jim Flett Wilson introduced the Shetland Community Screening Project, a bold initiative aiming to offer genetic screening to the Shetland population, to an audience of stakeholders, including senior members of staff from NHS Shetland, community leaders, private companies, and invested individuals. The project's vision is simple yet transformative: by identifying genetic risks early, the community can protect itself today and safeguard future generations.

The urgency of this project is underscored by findings from the Viking Genes research. Shetlanders, it turns out, are far more likely than people on the UK mainland to carry certain disease-causing genetic variants.

Some of these, such as the *BRCA2* gene linked to breast, ovarian, and prostate cancer, or the *KCNH2* gene associated with fatal heart rhythms, are over one hundred times more common in Shetland. Despite these risks, about half of those affected remain unaware of their genetic status, missing out on potentially life-saving treatments and interventions.

Building on the momentum of the VIKING I and VIKING II phases, which began returning genetic risk information to Shetlanders in 2023 and 2024, the project now seeks to screen 5,000 residents for up to 20 key genetic variants. This effort is not just about individual health; it's about community resilience. By identifying those at risk, the project can offer tailored support and medical care, helping people make informed decisions about their health and family planning.

Looking ahead, the team hopes to expand the screening to include severe inherited diseases such as Cohen syndrome, Batten disease, cystic fibrosis, and Wilson disease. Many of these conditions are incurable, but early knowledge can empower families and healthcare providers to take proactive steps. Within two years, the project aims to begin returning results to carriers of these variants, focusing especially on young adults who may not yet have children. This approach could help reduce the likelihood of passing on serious conditions to future generations.

The process of sharing results will be carefully staged. Initially, the focus will be on variants linked to cancer risk, followed by information relevant to family planning, and eventually, potentially the return of more advanced genetic information such as polygenic risk scores. These scores, still in the research phase, promise to become a cornerstone of genomic medicine in the years ahead.

Viking Genes Shetland committee:
Lindsay Tulloch, Valerie Nicolson, Sandra Laurenson, Elaine Jamieson, Peter Malcolmson.

Community support is vital to the project's success. With the endorsement of Professor Jim Flett Wilson, a dedicated committee of local volunteers (pictured above) is working to raise the £1 million needed to fund the initiative. Fundraising efforts are already underway, with local events and individual donations helping to build momentum.

The Viking Genes Shetland Community Screening Project has now received the backing of every Shetland parish and isle through support of all 18 island Community Councils, joining the local MSP and MP in calling for the Shetland population to become the first part of Scotland to be genetically screened as part of a preventative healthcare campaign.

Charlotte Anderson, on behalf of **Northmaven Community Council** in her letter of support wrote: "We are greatly encouraged by the evidence your research team has provided, revealing a significantly higher prevalence of disease-causing genetic variants within Shetland's population, with conditions such as BRCA2-related cancers and heart rhythm disorders posing real risks to families in every part of our community. Offering free genetic screening to Shetland residents stands to save lives through early intervention and provides reassurance to many who may otherwise remain unaware of their health risks.

We believe the project will make a profound difference to local health outcomes and overall wellbeing, particularly in our rural area. We are hopeful that further funding can be secured to realise the full ambition of this initiative."

Joanne Jamieson, representing **Sandwick Community Council** said "Scotland has a reputation for scientific innovation for the good of many. Your Viking Genes project embodies that spirit."

Dawn Ratter, for **Lerwick Community Council** emphasised the alignment with the **Shetland Partnership Plan**, stating that early identification of risk "exemplifies the Plan's commitment to preventative approaches and early intervention."

This Viking Genes Shetland Screening Project will move Shetland to the forefront of preventative medicine in the UK and help shape the future of UK health policy in preventative health screening in targeted populations.

Local MP Alistair Carmichael said, “The people of Shetland have a far greater risk of suffering from inherited genetic health risks than other population groups in the UK, and as such the benefit of genetic screening as a preventative healthcare strategy can deliver so much more here in Shetland than it can do anywhere else. The Viking Genes screen can save lives and improve the future health outcomes of potentially hundreds of families across our islands.

“I’m delighted to see that all 18 Community Councils representing the whole 23,000 population of Shetland have unanimously come out in support of this bold initiative and calling for action on the Viking Genes Shetland Community Screening Project, that would put Shetland and Scotland at the forefront of preventative medicine.

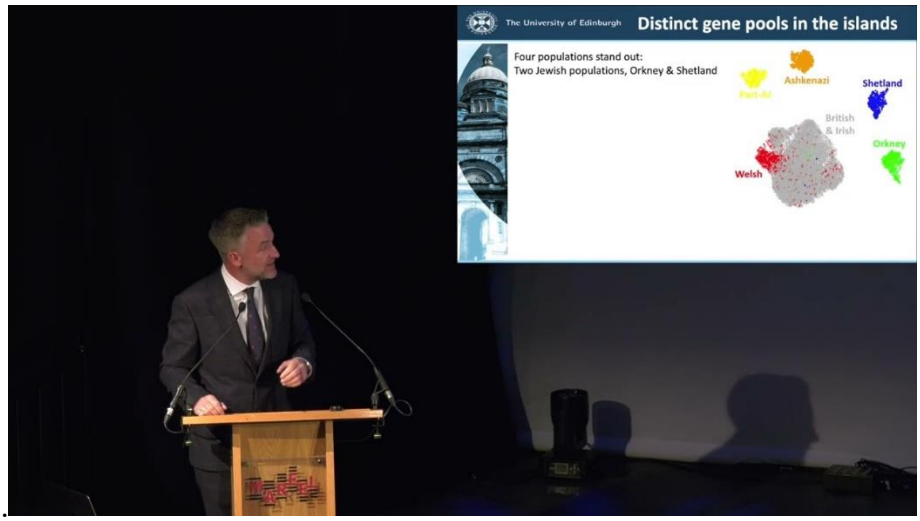
Improving the health outcomes of all of our people and the future generations of islanders is the most vital of actions our society can take and provides real benefit to our community and the future of Shetland.”

Shetland MSP, Beatrice Wishart added, “I am very encouraged by the aim of the project as we already know that there are genetic predispositions within the Shetland community. Screening will have long term value with future generations benefiting from preventative action and medicine.”

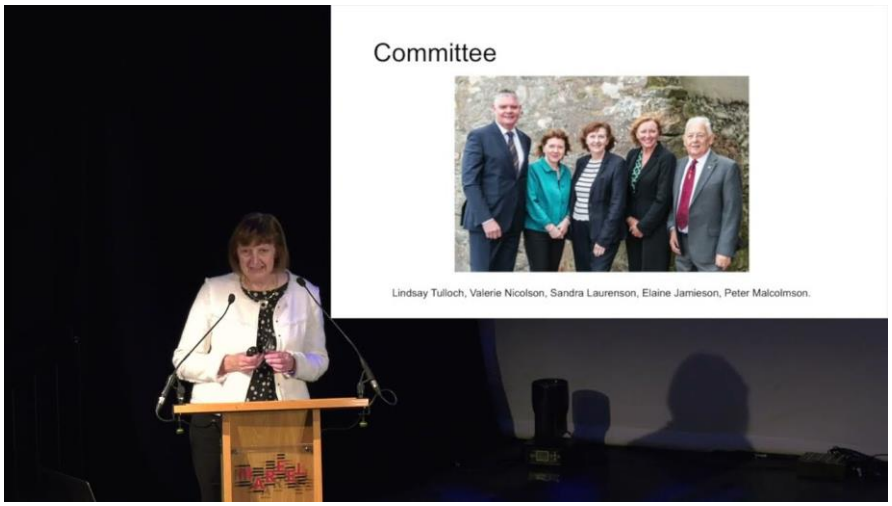
The project also has the support of **NHS Shetland**, with **Health Board Chair Gary Robinson** describing the prospects as “really exciting” with a “phenomenal” potential for early detection and **Chief Executive Brian Chittick** noting that the project “could really reform what we are doing in the prevention realm.”

In contrast to the recent **UK National Screening Committee (UK NSC)** decision to reject widening access to prostate cancer screening across the UK, the Viking Genes screen is based on more conclusive genetic testing to identify people at any age that have an elevated risk of the diseases in question.

If successful, the Shetland Community Screening Project will place Shetland at the forefront of preventative medicine in the UK. The benefits are far-reaching: improved community health, lives saved, and a higher quality of life for many residents. By embracing genetic screening, Shetland is taking a proactive step toward a healthier, more informed future.



Watch Professor Jim Flett Wilson make the case for genetic screening in Shetland at the launch of the Shetland Screening Community Project in May.



Watch Sandra Laurenson OBE - Viking Genes Shetland fundraising chair - tell the audience in Lerwick how the Shetland community can help the project.

If you can help, let's get talking, we are grateful for all the community help. Email **viking@ed.ac.uk**

Visit our Shetland Community Screening page*

Pharmacogenetics: the future of genomic medicine

Professors Jim Flett Wilson, Tim Aitman (University of Edinburgh), and Dr David Twesigomwe (University of the Witwatersrand, South Africa), analysed data from over 1,800 people from Orkney and Shetland who took part in Viking Genes, looking at variants in genes which influence the way drugs work in our bodies. This is part of a growing field called pharmacogenomics.

They looked at 41 genes known to play a role in how drugs are absorbed, processed, and used by the body. Everyone in the study had at least one known genetic variant that could affect how they respond to certain medications. For some drugs, up to half of the participants had genetic findings that indicate they might require a change in the dose or type of medication. The most commonly affected drug-related genes were those involved in processing common medications like antidepressants, painkillers, blood thinners, and statins.

Dr Twesigomwe said:

“Pharmacogenomics can enable healthcare teams to obtain an important piece of the puzzle to make the optimal choice of drug/dose for each patient, the first time. For example, we observed that 7.8% of the Shetlander participants and 8.6% of the Orcadian participants in the study had no functional copies of the important CYP2D6 gene. These participants are predicted to be CYP2D6 poor metabolisers and may therefore not respond adequately to some pain medications such as codeine and tramadol, while they could be at a risk of side effects to some antidepressants (e.g. paroxetine). For context, the proper functioning of CYP2D6 is vital to the response of about 20% of commonly prescribed medications. Broadly, this paper highlights the extent of known and novel variation across important genes present in state-of-the-art pharmacogenomic tests. This research can inform the application of pharmacogenomic tests and future studies on their clinical utility with regard to improving drug therapeutic outcomes across the Scottish Isles.”

Read more here*

Committee spotlight: Peter Malcolmson OBE

I am now 86 years old and have lived in Shetland all my life, student days apart. I have spent over 40 years of my working life in local government, some 30 years as the Council's Director of Social Work, and, on retirement, some 10 years as an elected member so I think that I can claim a good knowledge of, and grounding in, my community. I have also served on the Board of NHS Shetland and was Chairman of Voluntary Action Shetland and was Trustee of Shetland Charitable Trust for a four-year term.

I have spent a lot of my spare time in supporting community initiatives by helping to fund-raise for good causes, starting with raising funds over several years to provide a village hall for my immediate community. Following that, I chaired a group that raised funds to provide a McMillan Nurse for NHS Shetland. In 2006 to 2007 I also chaired a committee that raised 1.6 million pounds to provide a CAT Scanner for the Gilbert Bain Hospital here in Shetland, and, in recent years, have raised funds for the Anthony Nolan and Teenage Cancer Trust Charities.

What made you interested in helping Viking Genes with their plans for screening in Shetland?

I attended the lecture that Professor Jim Wilson gave on Viking Genes in Lerwick in September 2024 and the following day contacted Ms Sandra Laurenson (who had also attended the lecture) and we agreed that we had to do something to support Prof Wilson. We have therefore been engaged over several months in setting up the Viking Genes Community Screening Project.

Viking Genes Fundraising Update

Business and community funding is key to us continuing our work across all of the Scottish islands. The Viking Genes Shetland fundraising drive has shown in just a few months what can be done, but we need to raise much more if the screening project is to be become a reality.

Thanks to a grant of £15,000 from Viking Energy's Shetland Community Benefit Fund, we have now exceeded £100,000, so 10% of the way to our total.

Professor Jim Flett Wilson said: "On behalf of Viking Genes, I am delighted with the £15k funding from Viking Energy's Shetland Community Benefit Fund. I think our Shetland Community Screening

Project - which this will support - is the very definition of a community benefit and and I was happy to receive such widespread support for our project."

After the success of the Viking Genes Fund, and latterly, the launch of Viking Genes Shetland Community Screening Project, we felt it was time to create two further Viking Genes funds, so we can support our projects across all the Scottish isles within the Viking Genes family.

The Viking Genes Fund now will be used to fundraise for Viking Genes Shetland, and the Viking Genes Hebrides and Viking Genes Orkney Funds for their respective future projects – Prof Wilson believes both island groups need screening programmes.

Shetland Community Screening Project has a superb committee working to raise funds for us, but we are looking for other supporter partners across the Hebrides and Orkney to help raise funds for their dedicated Viking Genes projects through events and community and business support. If you can help, let's get talking, we are grateful for all the community help. Collectively, it will make a difference! Email **viking@ed.ac.uk**

Visit our Support Viking Genes page to learn more*

Highlights from Viking Genes Shetland fundraising in 2025

North Yell Development Council (NYDC) donated a magnificent £25k to Viking Genes Shetland - our largest donation so far. Prof Jim (left) is pictured receiving the cheque from Andrew Nisbet and Alice Mathewson.

Robert Anderson's remarkable and inspiring sail to fundraise for Viking Genes in his 100-year-old fishing boat, the Pentland Skerries, which he personally rebuilt from the keel-up during lockdown in Tresta raised an incredible £4,107.92.

**We are incredibly lucky to be supported by some very special people.
This recent photo taken at the Wastside (s)miles fun run/walk in Skeld, which raised a Brilliant £3,000 for Viking Genes Shetland, encapsulates the spirit of this support:
(from the left) Peter Malcolmson, Robert Anderson, Sharon Deyell, and Sandra Laurenson.**

A family gathering, called 'The Sutherland Doo III', raised an incredible £1,015 for Viking Genes Shetland. Pictured are many direct descendants of the late Magnus Sutherland (1876-1954) and his wife Catherine Johnson (1884-1942) of Voe, Shetland.

Viking Genes continues to grow on social media.
We now have over 4,100 followers on Facebook. Thank you!

Follow us on:
Facebook
Instagram

Contact Us

Our research team is based at the University of Edinburgh, in the Usher Institute.
If you ever have any questions, you can email us at viking@ed.ac.uk

Your Data Privacy

We want to make sure you're aware of how we protect your data when conducting our research. For more information about how we use your data and keep it safe, please see our Privacy Policy at www.viking.ed.ac.uk/privacy-notice, or let us know if you'd like to have a copy posted to you.

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