**Shetland Community Screening Project – Frequently Asked Questions**

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**1. What is the Viking Genes Study?**

The Viking Genes Study is a long-running research project led by the University of Edinburgh. Over the past 20 years, it has analysed the DNA of more than 10,000 people from Scotland's island communities, including Shetland. The study has produced over 250 academic papers and has uncovered unusually high rates of certain genetic health risks in island populations.

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**2. Why is genetic screening important for Shetland?**

Research shows that Shetlanders have a higher prevalence of specific genetic variants linked to serious but treatable diseases. Early identification allows individuals to access preventative medical care, reducing illness and saving lives. Many conditions can be managed effectively if detected early.

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**3. What is the Shetland Community Screening Project?**

It is a new initiative aiming to offer free genetic screening to 5,000 adult residents of Shetland. The project focuses on identifying individuals with actionable genetic variants so they can access NHS care pathways for prevention or treatment.

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**4. Who can take part?**

Any adult living in Shetland (aged 16+) can participate — regardless of whether they have Shetland ancestry. Previous Viking Genes participants (over 3,000 people) do not need to be screened again.

There is no selection policy – only "first come, first served".

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**5. What genetic conditions will the screening look for?**

The project will test for a number of known variants that are particularly relevant to Shetland. These include:

**Actionable variants (treatable or manageable):**

- **BRCA2** – increased risk of breast, ovarian, and prostate cancer
- **KCNH2** – heart rhythm disorder linked to sudden cardiac arrest

- **TTN** – heart muscle disease leading to heart failure
- **ATP7B** – Wilson disease (build-up of copper in the organs)
- **HFE** – Haemochromatosis (build-up of iron in the organs)

**Carrier variants (important for family planning):**

- Batten disease
- Cystic fibrosis

Carrier variants only cause disease if a child inherits two copies — one from each parent.

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**6. How many people are expected to benefit?**

Based on previous screening, we can predict that about **50 to 100 individuals** will be able gain access to important preventative healthcare they may not otherwise have known they needed.

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**7. What are the benefits of taking part?**

- Early detection of treatable genetic risks
- Access to established NHS care pathways
- Peace of mind for those with no concerning findings
- Potential benefits for family members who may also be at risk
- Contribution to research that shapes future healthcare policy

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**8. How will the screening process work?**

Participants will:

1. Register online via the Viking Genes website
2. Provide online consent
3. Receive a saliva (spit) kit by post
4. Return the sample for testing
5. Access results via a secure online dashboard

6. Be referred into NHS pathways if an actionable variant is found or benefit from peace of mind, if not

**The project also plans community outreach days to increase accessibility and recruit people across the islands.**

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**9. How long will it take to receive results?**

The aim is for participants to receive results within **three months** of returning their saliva sample.

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**10. How is the project funded?**

The total cost through 2029 is **£1.8 million**.

- The University of Edinburgh contributes **£800k (45%)**
- **£1 million** to be raised through donations and community support

Costs include:

- 25%: testing kits and laboratory work
- 65%: salaries for a 3.5-person project team
- 10%: miscellaneous and NHS-related costs

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**11. What is the Viking Genes Fund?**

It is a restricted charitable fund within the University of Edinburgh Development Trust. Donations can only be used for Viking Genes-Shetland–related work. If donor wishes cannot be met, funds may need to be returned.

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**12. How is the Shetland community involved?**

A local volunteer committee, led by Sandra Laurenson and endorsed by Professor Wilson, supports fundraising and awareness. Additional community-led fundraising has already raised over £100,000 (as of January 2026).

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**13. What is the long-term goal of the project?**

- Improve health outcomes in Shetland

- Provide a model for preventative genetic screening across Scotland
- Strengthen the evidence base for community-wide genetic health programmes
- Influence future public health policy
- Advance genomic medicine as a routine part of healthcare

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**14. How will the project data be protected?**

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.

Our privacy notice tells you what to expect when Viking Genes collects your personal information. Download it via this link: Privacy Notice.

You can also learn how we protect the data of our volunteers by visiting: FAQs - Protecting Your Data.

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**15. When will the project start?**

Once sufficient funds are pledged, a project team will be recruited. Preparation is expected to take up to one year, followed by a three-year screening and results-return programme.