



FarGen: Bioresource From the Faroe Genome Project

BIORESOURCE PAPER

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ABSTRACT

The Faroe Genome Project (FarGen) explores the genetic variation within the isolated population of the Faroe Islands. FarGen is an open bioresource comprising 3% of the entire Faroese population, available for further investigation of both rare and common diseases. The 1,541 volunteers include representatives from all sub-regions of the islands, and health- and socio-demographic data is collected by questionnaire, Multi-Generation Registry, Diagnostic-Registry, and National Registry. The FarGen-infrastructure is already open to research teams, and is being used in research of various complex disorders. Future aim is to reach 5000 samples i.e. 10% of the entire Faroese population.

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KEYWORDS:

Whole-blood; DNA; genetic data; health- and socio-demographic data

TO CITE THIS ARTICLE:

Gregersen NO, Apol KD, Weihe P, á Steig B, Andorsdóttir G. FarGen: Bioresource From the Faroe Genome Project. *Open Journal of Bioresources*. 2021; 8: 1, pp. 1–6. DOI: <https://doi.org/10.5334/ojb.71>

(1) OVERVIEW

PROJECT DESCRIPTION

In 2016 the Genetic Biobank of the Faroe Islands initiated the Faroe Genome Project (FarGen) – an open bioresource comprising 3% of the entire Faroese population of 53.000 individuals. Volunteers have been recruited with the goal to promote genetic research by making sequencing- and metadata available to research teams, this to explore the hypothesis that an isolated population may reveal unprecedented details about rare and common diseases [1–4]. All volunteers will be included in the reference-panel of genetic variants within the Faroese population; however, they must re-consent for future use in phenotypic associated research.

The 1,541 volunteers include representatives from all sub-regions of the islands, 61.5% are women, mean-age at enrolment was 47.9 years. All have donated a blood sample for genome sequencing. Metadata is collected by different sources: questionnaire (socio-demographics, morbidity, lifestyle etc.); Multi-Generation Registry (family-relations); Diagnostic-Registry (confirmation of self-reported health-status); National Registry (confirmation of home address, vital state of participants before re-contacting etc.). The self-reported health status shows a healthy/disease ratio of almost 1:1, comprising a diverse set of diseases within in the ICD-10 coding system. Participants are generally interested in participating in all future health-related research, and are mainly engaging in the project for altruistic reasons. The FarGen-infrastructure is already open to research teams and is being used in research of hereditary breast and ovarian cancer, inflammatory bowel disease, and attention deficit hyperactivity disorder. Future studies will also show the degree of genetic relatedness between the individuals in the FarGen population sample.

CLASSIFICATION (1)

Human.

SPECIES

Homo sapiens.

CLASSIFICATION (2)

Biological samples and associated data.

CONTEXT

Spatial coverage

The collected samples represent the whole population of the Faroe Islands (*Figure 1*).

Latitude: 62.0107° N

Longitude: 6.7741° W



Figure 1 The Faroe Islands located in the middle of the North Atlantic Ocean between Iceland, Scotland and Norway.

Temporal coverage

The FarGen phase I collection started on September 19th, 2016, and ended in 2018, February 5th. The next collection phase is planned to start in the fall of 2021.

Temporal coverage for accessibility

The bioresource is available since January 2019 and will continue indefinitely. Research project using FarGen bioresources will have defined timelines.

(2) METHODS

STEPS

Volunteers had three ways for signing up: 1) on the FarGen-homepage, 2) by contacting the FarGen-coordinator, or 3) by turning up to local information meetings. The agreements to give a whole-blood sample and filling in a mandatory questionnaire were obtained by written informed consent.

Peripheral blood samples (20 ml) were collected in EDTA tubes and stored as whole-blood within 12 hours, either at -40°C for DNA extraction within 7 days, or at -80°C for long-term storage. Meta-data was collected according to the Minimum Information About Biobank data Sharing [5]. All samples and meta-data are registered with new sample ID in the Progeny system in compliance with the General Data Protection Regulation (GDPR) requirements.

DNA is extracted for whole-exome or whole-genome sequencing using an automated method, followed by next-generation sequencing [6].

STABILIZATION/PRESERVATION

Blood samples are collected using EDTA tubes. DNA samples are stored in standard barcoded cryovials.

TYPE OF LONG-TERM PRESERVATION

Samples are frozen.

STORAGE TEMPERATURE

-80°C : Whole-blood

-20°C : DNA (extracted from blood)

SHIPPING TEMPERATURE FROM PATIENT/SOURCE TO PRESERVATION OR RESEARCH USE

Room temperature ($18-25^{\circ}\text{C}$).

SHIPPING TEMPERATURE FROM STORAGE TO RESEARCH USE

-80°C (on dry ice) and $0-4^{\circ}\text{C}$ (on ice).

QUALITY ASSURANCE MEASURES

Standard Operating procedures (SOPs) for all the processes; traceability of all the operations.

SOURCE OF ASSOCIATED DATA

Data associated with the biosamples/genetic data is collected via Questionnaire, and different registries: Diagnostic-Registry, Multi-Generation Registry, and National Registry. Data from registries is linked to the individuals through their social security number (SSN), and can be linked to the biosamples/genetic data by the clinical leader.

ETHICS STATEMENT

The activity of the Genetic Biobank is regulated by the Faroese government, act "Ll. nr. 62 frá 17. juni 2005". The informed consent sheet used for the recruitment has been approved

(L_01-08-2016) by the Faroese Scientific Ethical Committee (VSN: Visindasiðsemisnevndin). The Genetic Biobanks data management and storage is declared to the Data Protection Authority (DAT: Dátueftirlitið). Biosamples will only be destroyed if participants opt out; all biosamples and data of participants wishing to opt out will be deleted, however, data already published in peer reviewed journals will not be deleted.

CONSTRAINTS

Each research project, which requires access to samples/data or export of samples/data to another country must meet ethical and regulatory constraints of the Faroese government.

(3) BIORESOURCE DESCRIPTION

OBJECT NAME

The Faroe Genome Project

BIORESOURCE NAME

The FarGen-infrastructure

BIORESOURCE LOCATION

The Genetic Biobank of the Faroe Islands, J.C. Svabosgøta 43, 100 Tórshavn, Faroe Islands.

BIORESOURCE CONTACT

- fargen@fargen.fo
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- noomi@fargen.fo

BIORESOURCE URL

<https://fargen.fo>

IDENTIFIER USED

N/A

BIORESOURCE TYPE

General population sample

TYPE OF SAMPLING

Population based with the inclusion criteria 1) individual had to be 18 years of age or older 2) have Faroese residence or being of Faroese descent. No prior knowledge about health status or ethnicity was required, and the participation was voluntary.

ANATOMICAL SITE

N/A

DISEASE STATUS OF PATIENTS/SOURCE

Self-reported health status.

CLINICAL CHARACTERISTICS OF PATIENTS/SOURCE

N/A

VITAL STATE OF PATIENTS/SOURCE

National Register

CLINICAL DIAGNOSIS OF PATIENTS/SOURCE

Self-reported health status showed a wide range of diseases including metabolic disorders, cancer, mental disorders, heart diseases, respiratory diseases etc. Confirmation of diagnosis through medical records according to the ICD-10 classification.

PATHOLOGY DIAGNOSIS

N/A

CONTROL SAMPLES

About 50% of the participants are healthy women and men.

BIOSPECIMEN TYPE

Whole-blood, DNA, genetic-data (when available)

SIZE OF THE BIORESOURCE

1,541 individuals at present time, the estimated number at the end of the project is 5000.

RELEASE DATE

Data and biospecimens are currently available.

ACCESS CRITERIA

Researchers in the Faroe Islands or in other countries requesting access to biospecimens/data need to specifically sign a Template Material/Data Transfer Agreement (MTA/DTA) with the Genetic Biobank, submit and get approved a project protocol by the Faroese Scientific Ethical Committee (VSN) and the Data Protection Authority (DAT). Consent forms from the participants are needed for genetic studies.

Expenses associated are specified by the operative regulations of the Genetic Biobank and have to be covered. Researchers, academia and commercial, are required to acknowledge the FarGen-infrastructure in scientific publications.

(4) REUSE POTENTIAL

The FarGen cohort is an open bioresource infrastructure with various data available for research. Researchers in the Faroe Islands or in other countries will be granted access to de-identified biospecimens, genetic-data and meta-data provided all legal terms are met. Once a project has been approved by the Genetic Biobank (MTA/DTA), VSN and DAT, the researchers will be granted access to the data needed and biospecimens will be shipped if needed.

ACKNOWLEDGEMENTS

We would like to acknowledge all the participants in the FarGen project, all the local communities for hosting the information meetings at local schools and community centres, and all the funders of the project: The Faroese and Danish governments, the Faroese Research Council and the Betri Foundation. Further we thank Nina Djurhuus, Gunnrið Jóanesarson, Leivur N. Lydersen, and Ólavur Mortensen for great collaboration on this work.

COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHOR CONTRIBUTIONS

Gregersen Noomi Oddmarsdóttir: Creator, Project Manager, Collector of Data and Samples
Apol Katrin Didriksen: Creator, Information Coordinator, Collector of Data and Samples

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Published: 28 June 2021

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