Ílegusavnið
Genetic Biobank

How do I get access

Access to the registries is conditioned by:

- A contract with the Genetic Biobank
- A Clinical Responsible
- Approval from the Research Ethics Commitee (Registry research excluded)
- Approval from the Dátueftirlitinum

	Hospital	Genetic Biobank	Research Ethics Commitee	Data Protection Agency
Human genetics research projects				
Samples linked to genes and family relations		X	X	X
Samples not linked to genes and family relations	X		X	X
Provision of data for health-related reporting and other statistical purposes (Registry research)				
The Genetic Biobank registers: The Genealogical Registry The Diagnosis Registry The Tissue Registry		X		X
Register at the hospital	X	X	X	X

Contract with the Genetic Biobank

Genetic research in the tissues of people, registered in the Faroes is only to be performed by those appointed through contract by the Genetic Biobank, in accordance with national law. The Genetic Biobank has a monopoly on obtaining, preserving and handling organic tissue and diagnoses in genetical research. Before granting access to the registries, it is required that the Genetic Biobank and the research-concern's genetic research project has been approved by the Research Ethics Commitee, and having obtained informed consent, in accordance with the law of patient's rights.

Clinical responsible

Pursuant to legislation governing genetics research in the Faroe Islands, the Genetic Biobank, in conjuction with each approved research initiative, appoints a Clinical Responsible from within the National Health Care system to servure and review all personal data and diagnoses, including medical data from the National Pharmacy, general practitioners and specialists. The National Health Care system includes; Hospitals, general practitioners, specialists, the National Pharmacy and dentists. The Clinical Responsible's task is to secure the correctness of diagnoses granted to the Genetic Biobank, and giving informed consent to those, who give organic tissue to researchprojects.

The data responsible is the physical or legal person, public authority, institution, who single handedly or in collaboration with others decides, what purpose and with which tool, information can be processed. The data responsible is often the scientist or the institution responsible of the project and the processing of personal information about the participants. The dataresponsible is obliged to report the project to Data Protection Agency, and is responsible for the personal information about each participant is processed in accordance to the Act on Processing of Personal Data.

The data responsible has further tasks and obligations towards the registered persons, for example the data responsible is obliged to inform them about the safety regulations and duty to disclose all facts.

The Genetic Biobank is always the data responsible in projects linked to the Genetic Biobank.

Informing the Research Ethics Committee

The Research Ethics Commitee needs to be informed about all biomedical research, and their approval is required before the research project can begin. Bear in mind that for some other types of research, different authorities need to be informed, see table 1.

More information about the obligation to report to the Research Ethics Commitee and description of a biomedical researchproject can be found at
http://dnvk.dk/forskere/~/media/Files/cvk/vejledning%202014/PDFudgave%202014%20vejledning%20DOK1355342.ashx

The guide is in Danish and is found on the Danish Research Ethics Commitee website *(www.dnvk.dk)* and is of use, although Ílegulógin is a faroese special law and as such is not mentioned in the guide.

Informing the Data Protection Agency

Data Protection Agency needs to be informed if a resarch project deals with personal relations (sensitive information), and their approval is required. Sensitive information is, according to Act on Processing of Personal Data (Ll. nr. 73 of 08.05.2001):

- Skin colour and race
- Religious, philosophical or political views
- Criminal records, health and sexual conditions
- Association with labor unions etc.
- Social awkwardness and other strictly private conditions

Data Protection Agency seperates public and private research projects.

Registry research (without biological material)

Registry research (without biological material) is based on information in registries, for example medical records or a hospital record. The Genetic Biobank has 3 registries at hand:

- The Genealogical Registry
- The Diagnosis Registry
- The Tissue Registry

It's possible to do research in the Genealogical Registry and the Diagnosis Registry (without biological material) and according to Act on Genetic Research on humans , informing the Research Ethics Commitee is not required, however, you are obliged to inform Data Protection Agency. The Genetic Biobank is obliged to inform Data Protection Agency.