

## 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 Committee (Registry research excluded)

	Hospital	Genetic Biobank	Research Ethics Committee
Samples linked to genes and family relations		X	X
Samples not linked to genes and family relations	X		X
The Genetic Biobank registers: The Multi Generation Register The Diagnosis Registry The Tissue Registry		X	
Register at the hospital	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 Committee, 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 conjunction with each approved research initiative, appoints a Clinical Responsible from within the National Health Care system to secure 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 research projects.

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 data responsible 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 Committee 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 Committee and description of a biomedical research project can be found at <https://www.nvk.dk/forsker>

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

### **Data Protection Authority**

The Genetic Biobank is obliged to follow requirements from the Data Protection Authority if a research project deals with personal relations (sensitive information). Through information, dialogue, complaints and inspection the Data Protection Authority supervises that other public authorities, public and private companies, organizations and individuals follow the data protection legislation. Sensitive information is, according to the Act on Processing of Personal Data (Ll. nr. 80 07.06.2020):

- 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 Authority separates 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 Multi Generation Register
- The Diagnosis Registry
- The Tissue Registry

It's possible to do research in the Multi Generation Register and the Diagnosis Registry (without biological material) and according to Act on Genetic Research on humans, informing the Research Ethics Committee is not required, however, you and The Genetic Biobank are obliged to follow the requirements from the Data Protection Authority.