Norwegian Federated EGA node

The European Genome phenome Archive (EGA) is a resource for long term secure archiving and sharing of all types of potentially identifiable human genetic and phenotypic data.

EGA was launched by the European Bioinformatics Institute (EMBL-EBI) in 2008, and is now established as a prioritized Core Data Resource in the pan European Elixir data infrastructure.

EUROPEAN GENOME-PHENOME ARCHIVE

Main purpose of EGA and Federated EGA resources

- Provide **controlled access** to **sensitive data**
- Make sensitive data **Findable, Accessible, Interoperable and Reusable (FAIR)**
- Increase **visibility** of datasets, and facilitate **secure sharing** of these.
- Put the Data Controller (dataset owner) in **full control of granting access** to datasets, through a Data Access Committee (DAC) appointed for each dataset by the Data Controller.
- All **within the legal constraints** of sharing sensitive data.

GDPR.EU

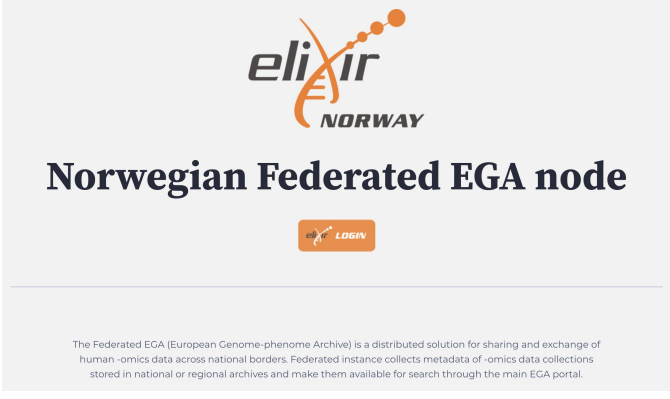
Federation of EGA nodes

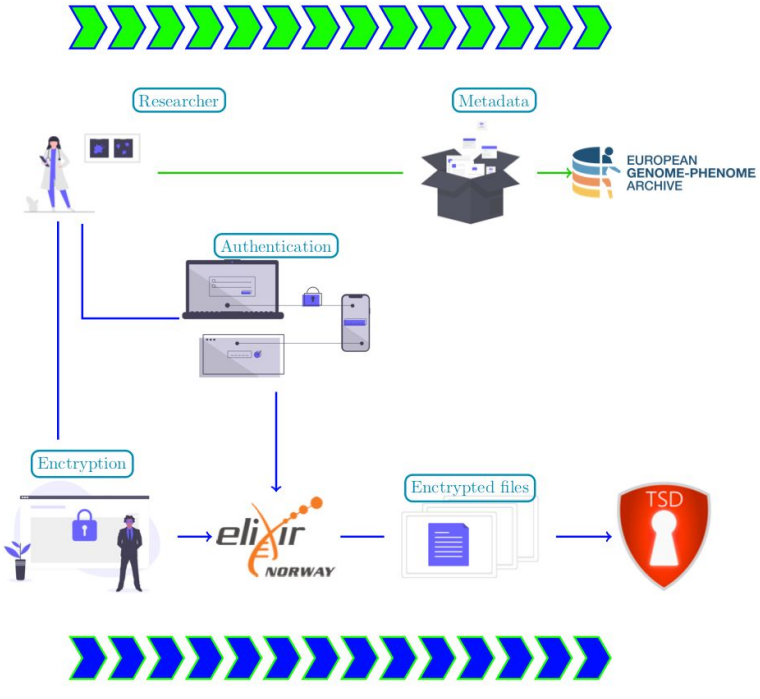
The European Union General Data Protection Regulation 2016/679 (GDPR) started to apply in 2018, and was implemented in Norway through the Personal Data Act (LOV-2018-12-20-116). Elixir Europe has since then collaborated to establish a federated network of archive nodes, where:

- No sensitive data leaves the country of origin when archived.
- Only anonymous meta-data describing a dataset as a whole is shared between the nodes.
- All information about individual samples are kept secure and encrypted in the country of origin.
- Sensitive data is only made accessible to a Researcher requesting access, after explicitly granted access from the appointed DAC, when the DAC has reached satisfactory terms for how the Researcher can use and process the data further. This will require contracts to be signed between the parties.

The Norwegian Federated EGA node

Elixir Norway has established a Norwegian node in the Federated EGA network, the NFEGA resource. NFEGA utilizes a common set of software modules, implementing standards from GA4GH for processing and storing sensitive data, that has been jointly developed by the Nordic Elixir nodes for the past 4 years. The NFEGA resource is hosted by University of Oslo, as a partner in the Elixir Norway consortium.





The **security of the data** stored in NFEGA and conformity of NFEGA procedures to Norwegian law, is guaranteed by the following:

- The Sensitive Data Archive is fully deployed inside the TSD infrastructure, Tjenester for Sensitive Data.
- All data both genomic and sample descriptions are stored with strong encryption, and provides an additional layer of security to what is provided from TSD itself.
- The NFEGA procedures and Risk and Vulnerability analysis (in Norwegian: “ROS analyse”) has been developed, reviewed and approved in close collaboration with University of Oslo’s legal representative, Data Protection Officer, Data Security Officer and the hosting institute.