## 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 <u>European Bioinformatics</u> <u>Institute</u> (EMBL-EBI) in 2008, and is now established as a prioritized <u>Core Data Resource</u> in the pan European Elixir data infrastructure.





## 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.





## Federation of EGA nodes

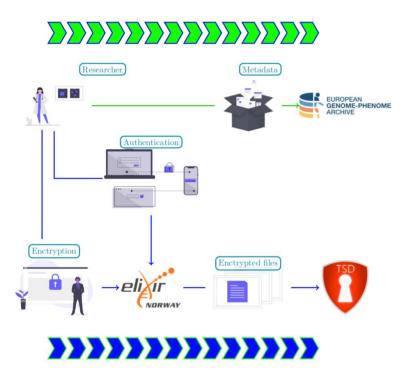
The European Union General Data Protection Regulation 2016/679 (GDPR) started to apply in 2018, and was implemented in Norway through the Personal Data Act (LOV-2018-12-20-116). <u>Elixir Europe</u> has since then collaborated to establish a federated network of archive nodes, where:

- 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 <u>FEGA Norway</u> resource. FEGA Norway utilizes a common set of software modules, implementing standards from <u>GA4GH</u> for processing and storing sensitive data, that has been jointly developed by the Nordic Elixir nodes for the past 4 years. The FEGA Norway resource is hosted by <u>University of Oslo</u>, as a partner in the <u>Elixir Norway</u> consortium.





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

- The Sensitive Data Archive is fully deployed inside the <u>TSD infrastructure</u>, 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 FEGA Norway 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.







