



FEGA Norway

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University of Oslo



Open Science Lunch
2026-01-29



Introduction to ELIXIR – how we work

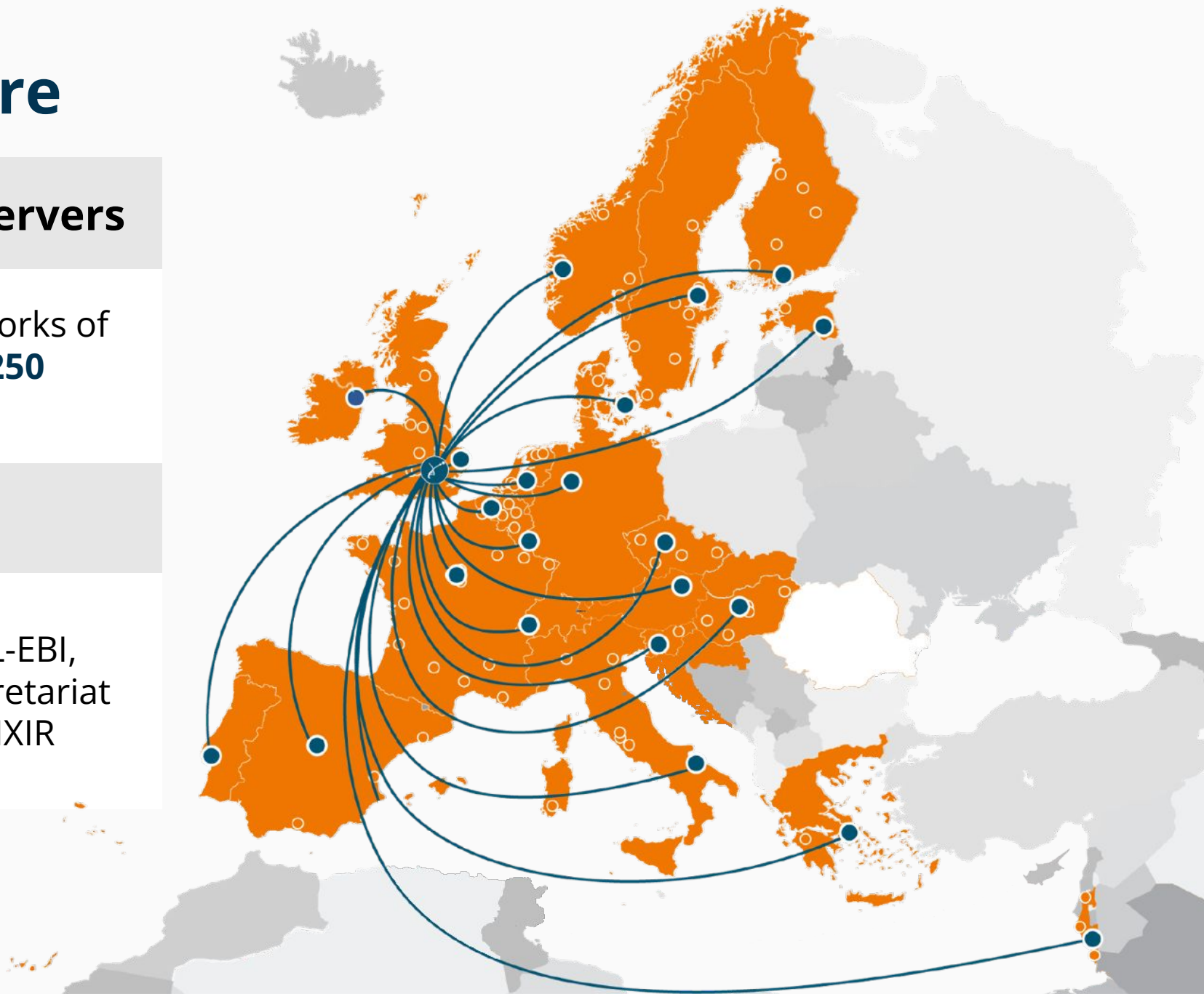
ELIXIR – who we are

23 Members and 2 Observers

ELIXIR Nodes form national networks of excellence, containing a total of **250** institutes/universities

1 Hub

The Hub, located alongside EMBL-EBI, Cambridge, UK, provides the secretariat and coordinating activities for ELIXIR



ELIXIR – what do we do

We build life science informatics capacity and infrastructure in Europe, connect and develop a network of experts and provide hundreds of high quality services and resources available to all



Databases



Training



Software tools



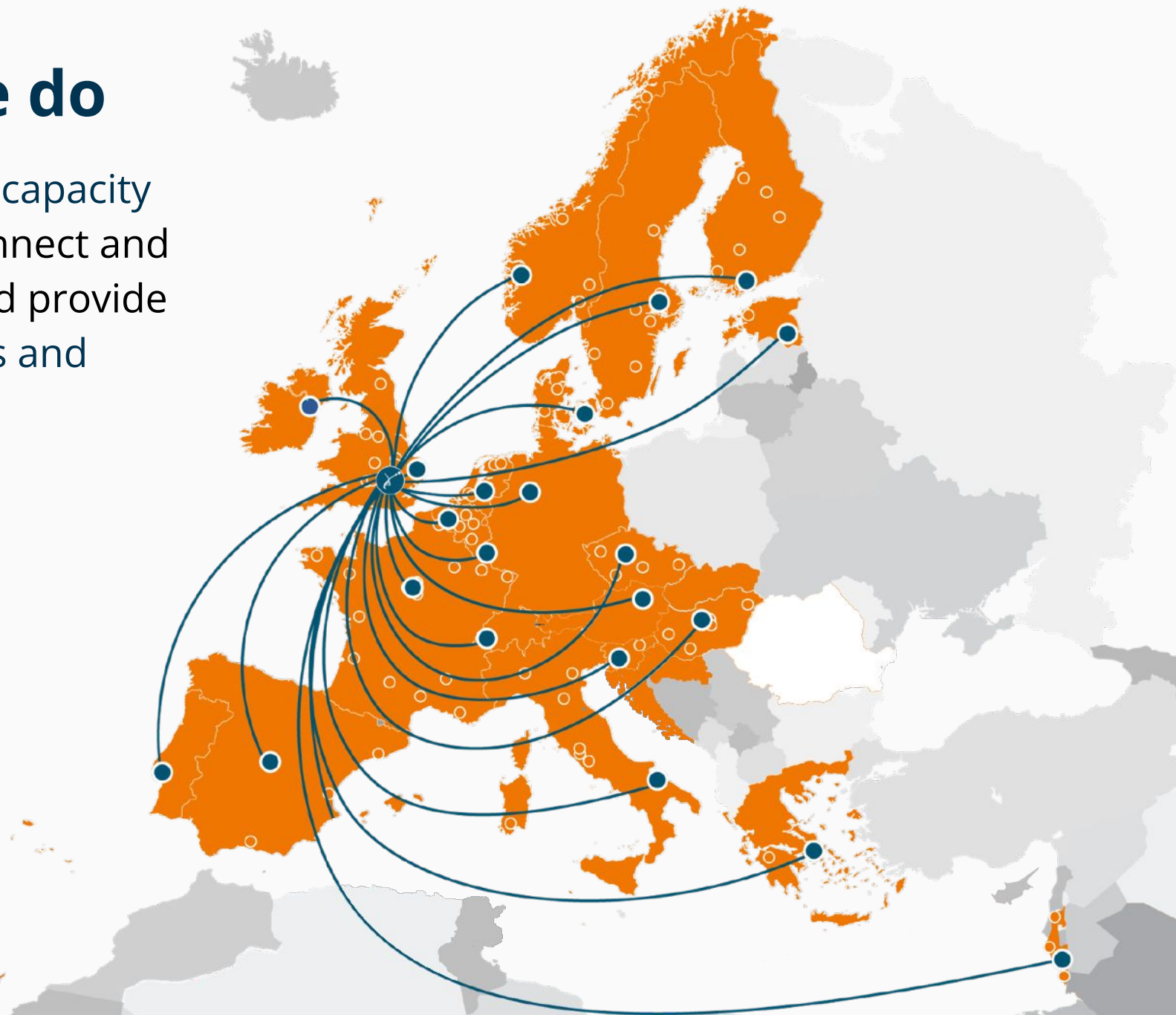
Data standards



Compute resources



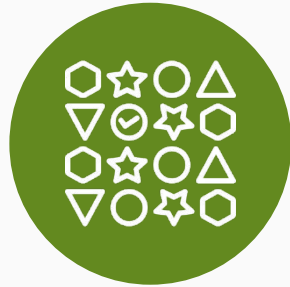
Scientific & technical experts



Data management challenges in life sciences



Data growth



Data diversity



Data location



Data sensitivity



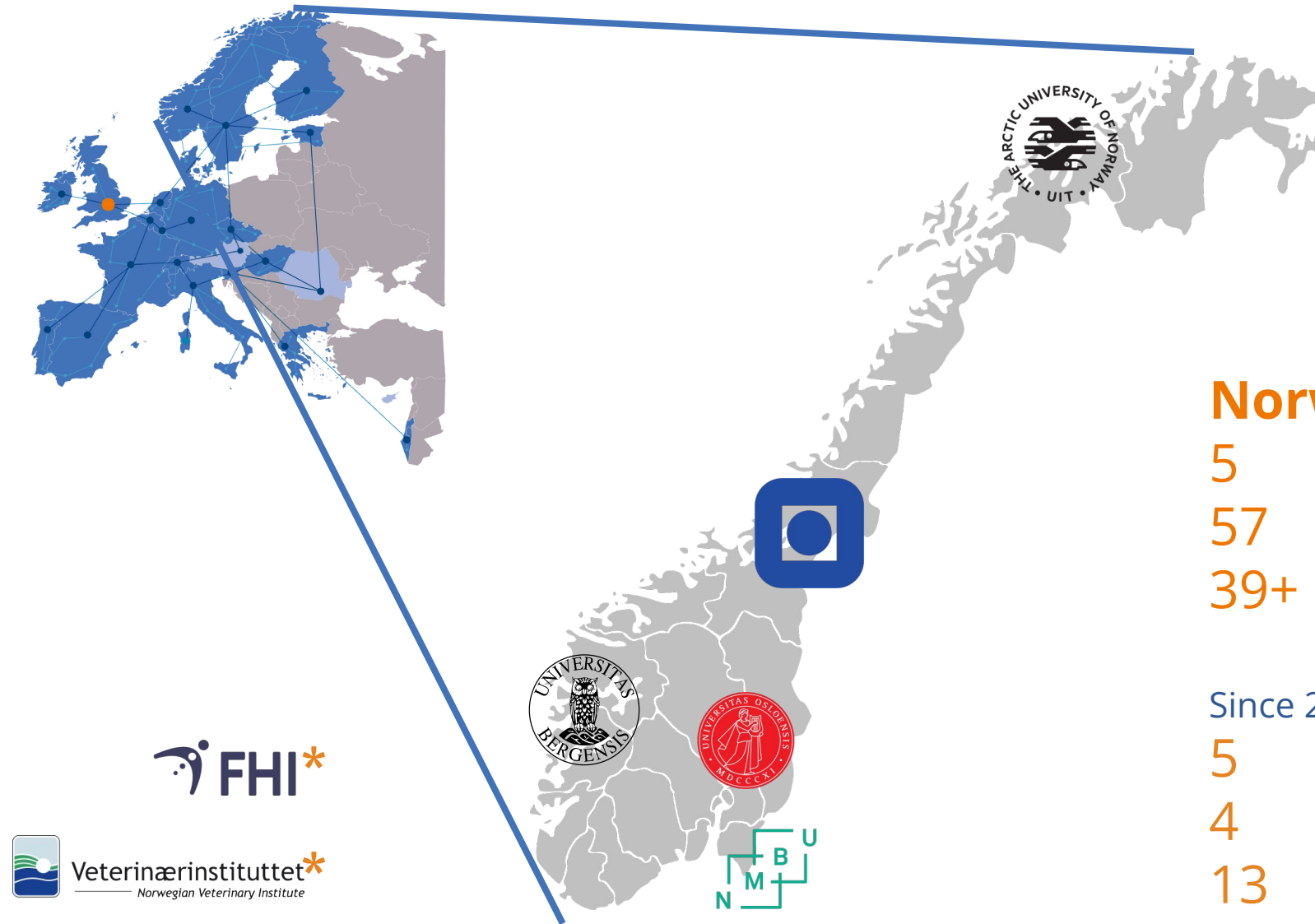
76%

of respondents state that without data shared on open repositories, they would not be able to offer their project or service

<https://f1000research.com/documents/10-828>

Small and medium-sized enterprises

ELIXIR in Norway



Norway

5 institutions
57 staff active
39+ software and tools

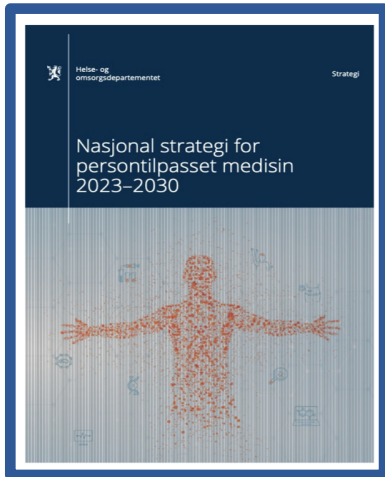
Since 2014:

5 INFRA grants
4 transnordic grants
13 HE/DE/H2020 grants

* ELIXIR₄ 2025

ELIXIR-NO is a key international player in the human data domain

Appointed by **Health Directorate (HDIR)** as Norway's executive representative in the **Genomics Data Infrastructure (GDI)** and **Genome of Europe (GoE)**



ELIXIR is coordinating EOSC-ENTRUST that brings together **SAFE, TSD, HUNT Cloud** to create a trusted research environment (TRE) blueprint for sensitive data handling in Norway



Norwegian Federated EGA (**FEGA Norway**) for sensitive human data is now **operational**, first datasets are archived

Nordic collaboration on sensitive data strengthened through NeIC projects



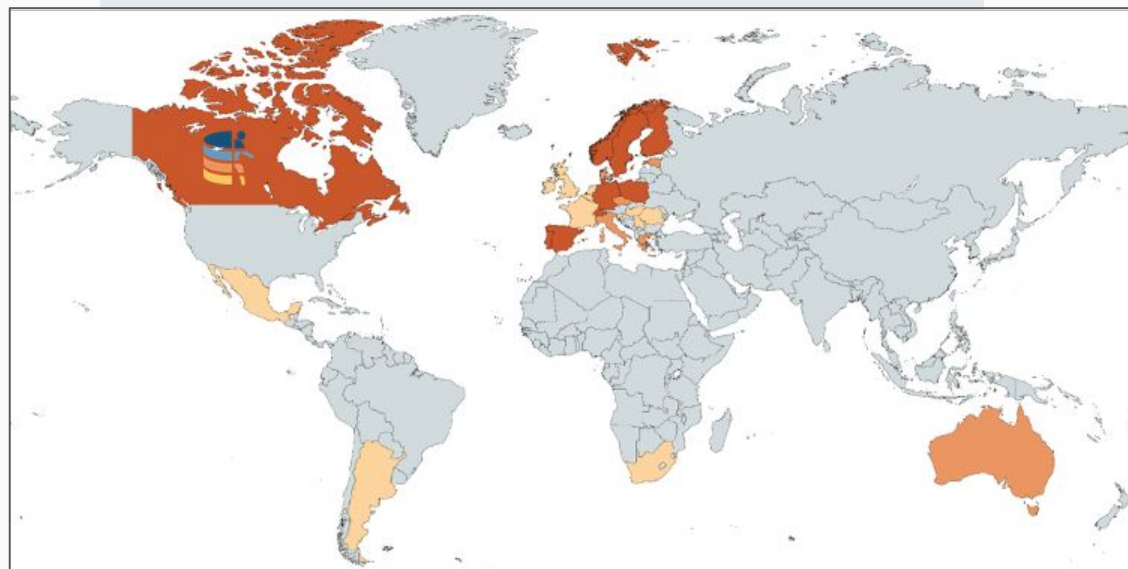


Introduction to FEGA and FEGA Norway

Federated EGA – February 2025

Federated European Genome-phenome Archive (EGA) strives to support the discovery of and secure access to human data globally, while respecting national data protection regulations, with the goal of accelerating disease research and understanding and improving human health.

>24 nodes engaged
and counting!



-  Central EGA node
-  Federated EGA node
-  Signed FEGA Collaboration Agreement
-  Engaged in work to establish a FEGA node
-  Expressed interest in joining FEGA Network
-  Data available

Status as of 17 Feb 2025



Central EGA



Data available



Signed FEGA
Collaboration Agreement



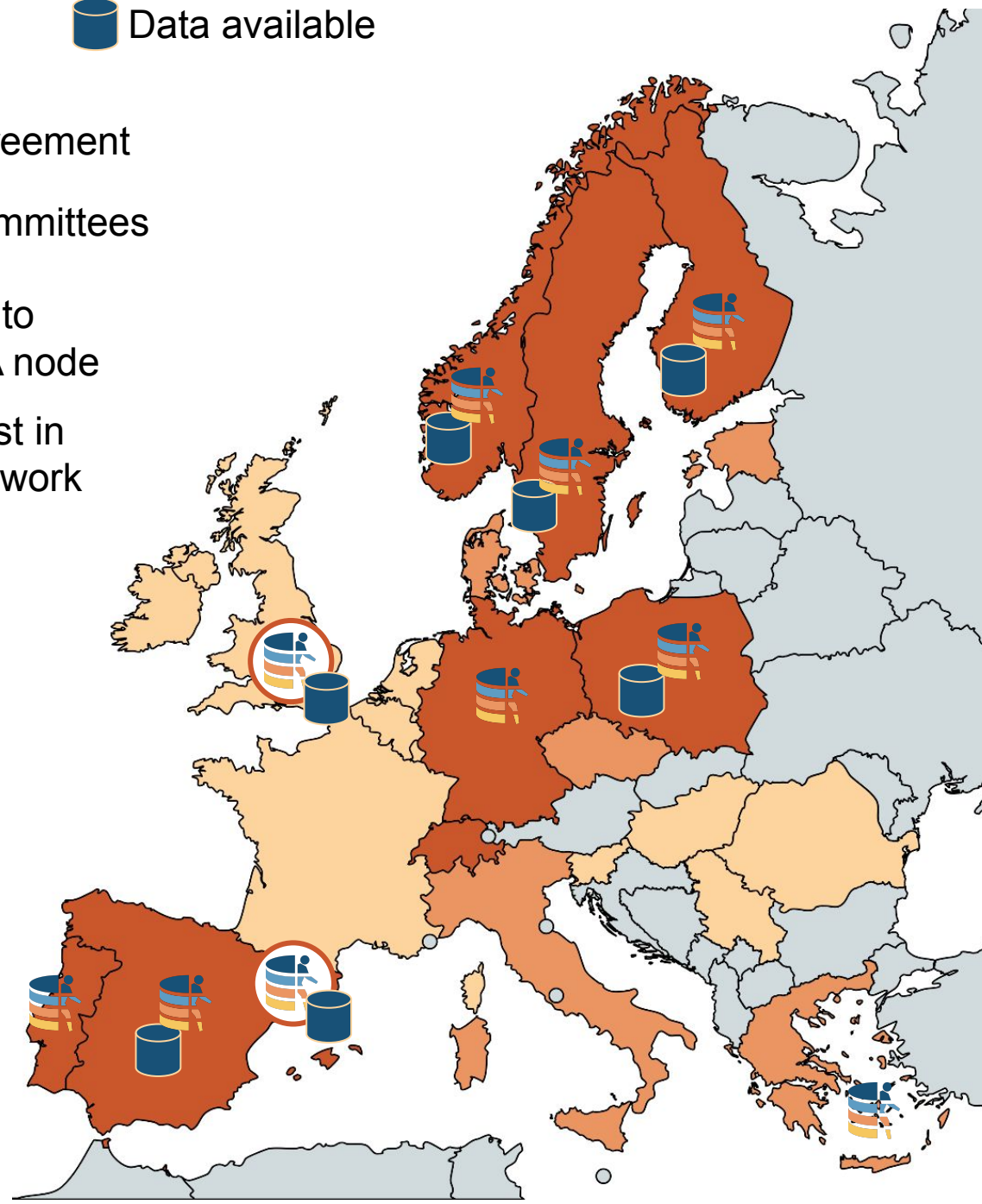
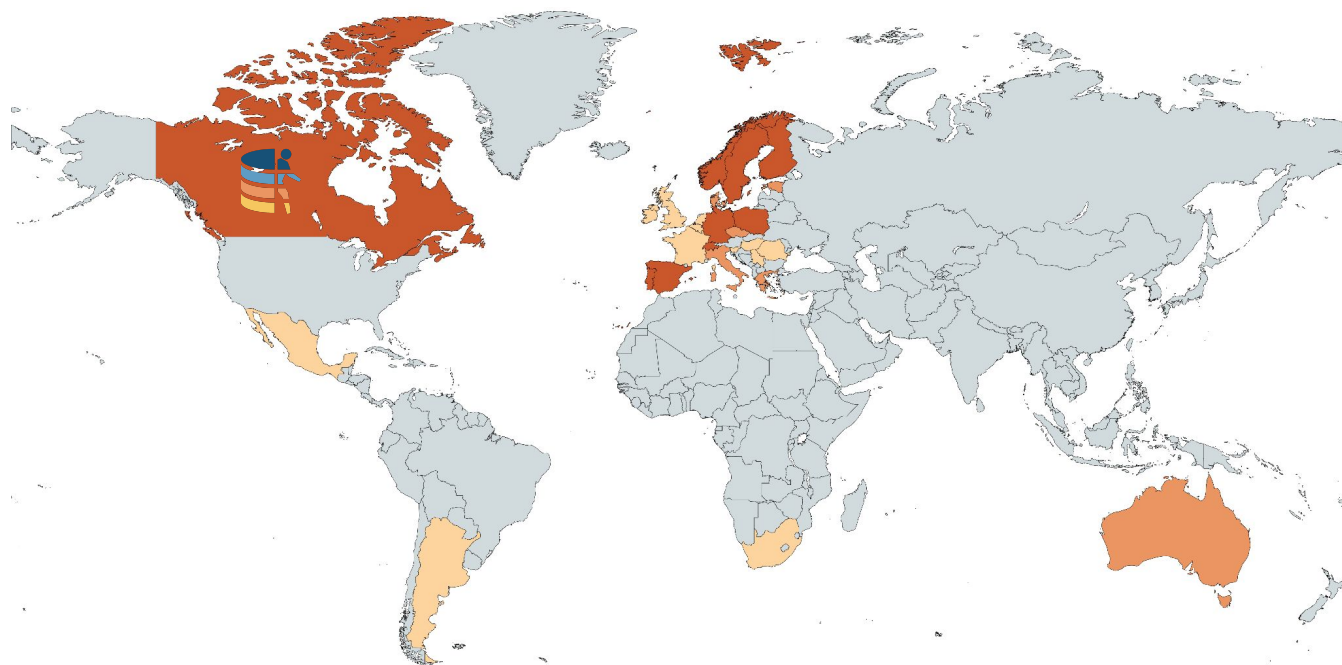
Joined FEGA Committees



Engaged in work to
establish a FEGA node



Expressed interest in
joining FEGA Network

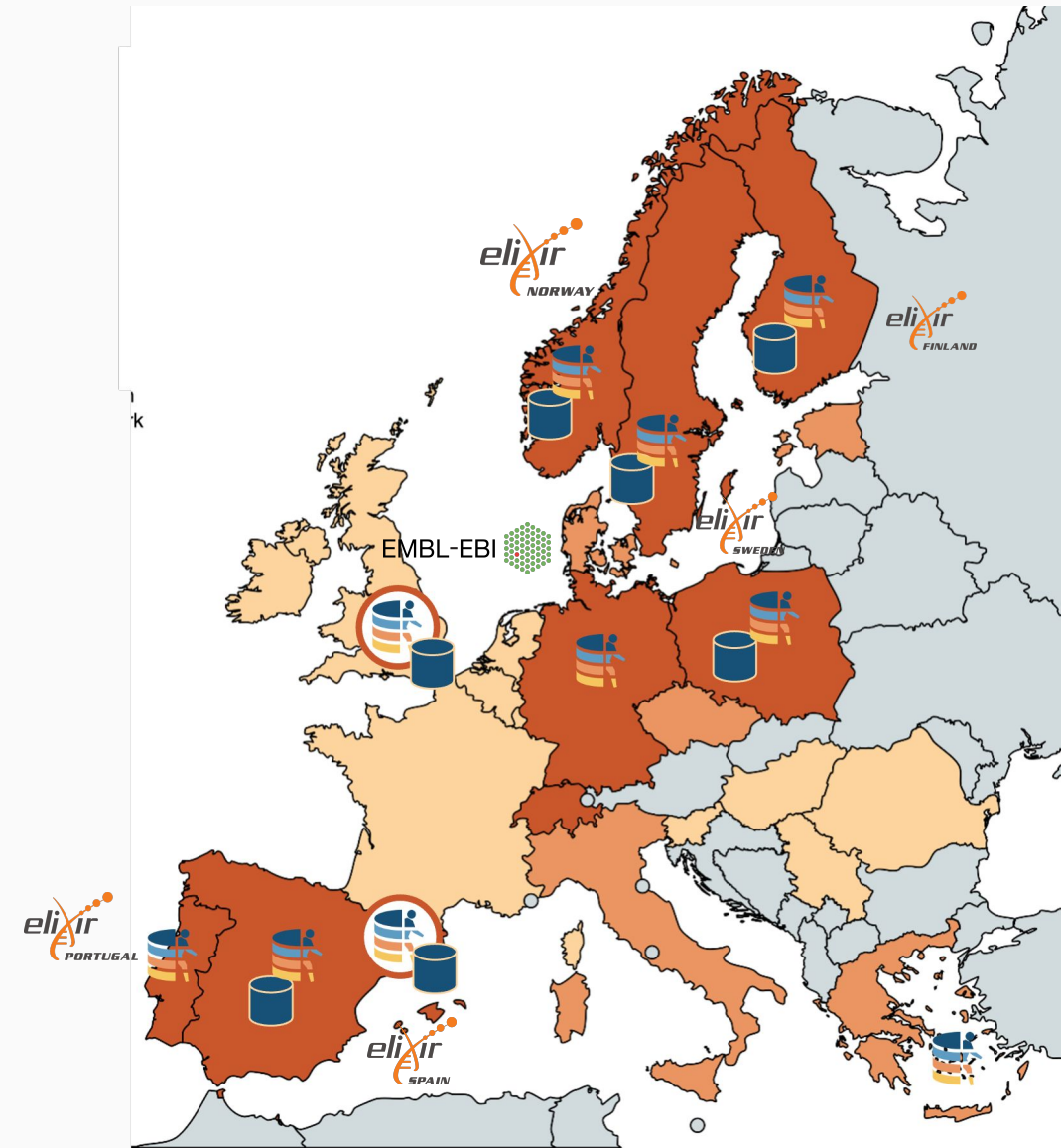


Federated EGA – February 2025

Institutes from Finland, Germany, Norway, Spain and Sweden are first the nodes of the Federated European Genome-phenome Archive, one of the largest international networks for discovery of sensitive human data

FEGA Norway firstly launched in 2022

FEGA Norway is a service by ELIXIR Norway. University of Oslo, as a partner institution in ELIXIR Norway, is hosting the service relying on the TSD infrastructure for sensitive data. ELIXIR Norway is a consortium of 5 Norwegian universities and is coordinated by University of Bergen.



First



submitters and adopters

In production since September 2023

First submission completed February 2024

← → ↻ ega.elixir.no/researcher_guide.html ☆ Relaunch to update ⋮

Institutions that has endorsed FEGA Norway

- The Oslo University Hospital (OUH) research leadership has for all researchers at the institution endorsed the use of FEGA Norway as a means for FAIR archiving and sharing of sensitive human data for research purposes.
- The Cancer Registry of Norway (CRN), formerly part of OUH, now a separate unit in the National Institute of Public Health, has approved FEGA Norway as a Controlled Access data repository for several CRN research datasets.
- The Haukeland University Hospital (HUH) has endorsed the use of FEGA Norway as a means for FAIR archiving and sharing of sensitive human data for research purposes through depositing multiple datasets from several projects in the FEGA Norway node.
- University of Bergen (UiB) has deposited biomedical datasets in FEGA Norway for FAIR archiving and sharing of sensitive human data for research purposes.
- Norges teknisk-naturvitenskapelige universitet (NTNU) has deposited biomedical datasets in FEGA Norway for FAIR archiving and sharing of sensitive human data for research purposes

 feqa-norway-support@elixir.no

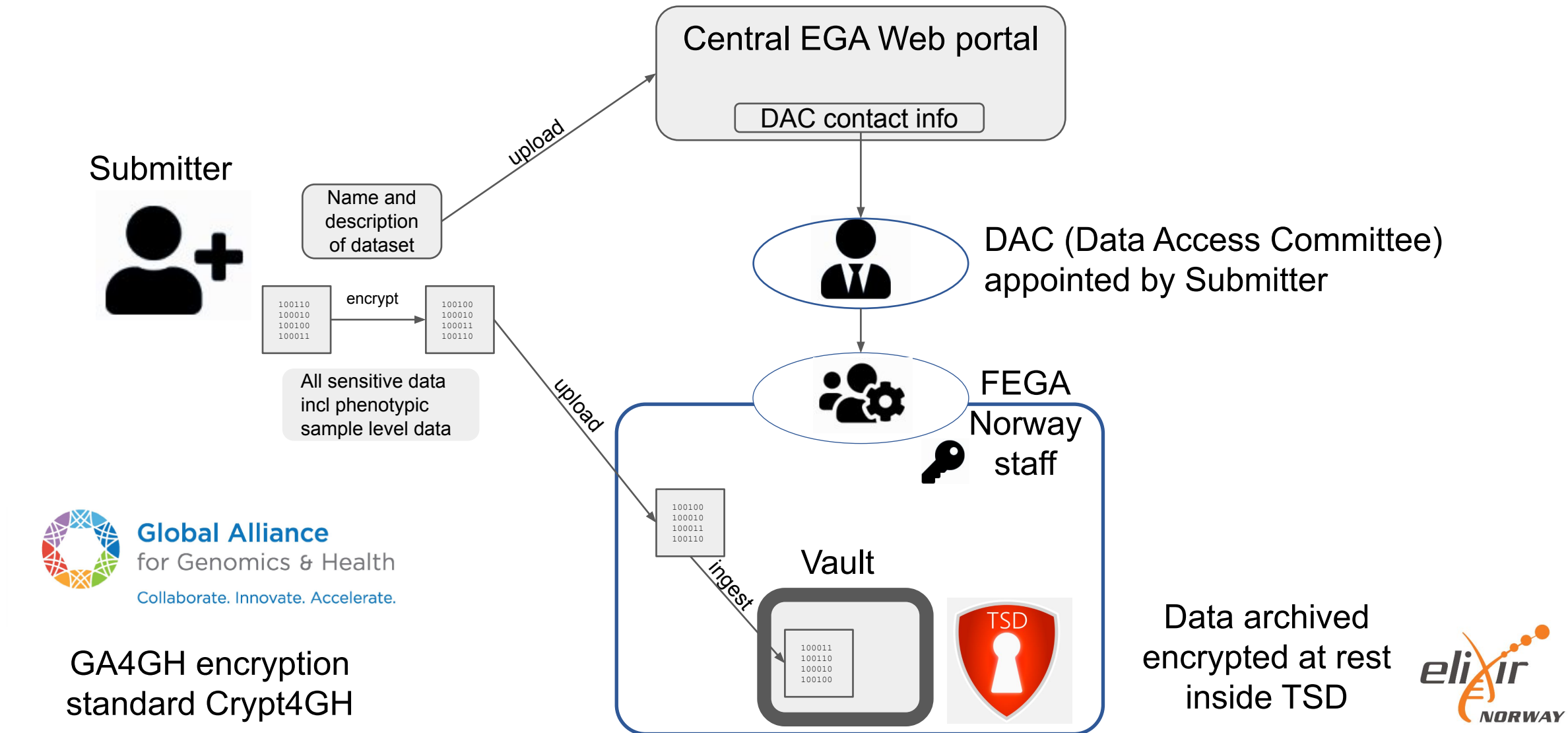
=> with currently 15 datasets released



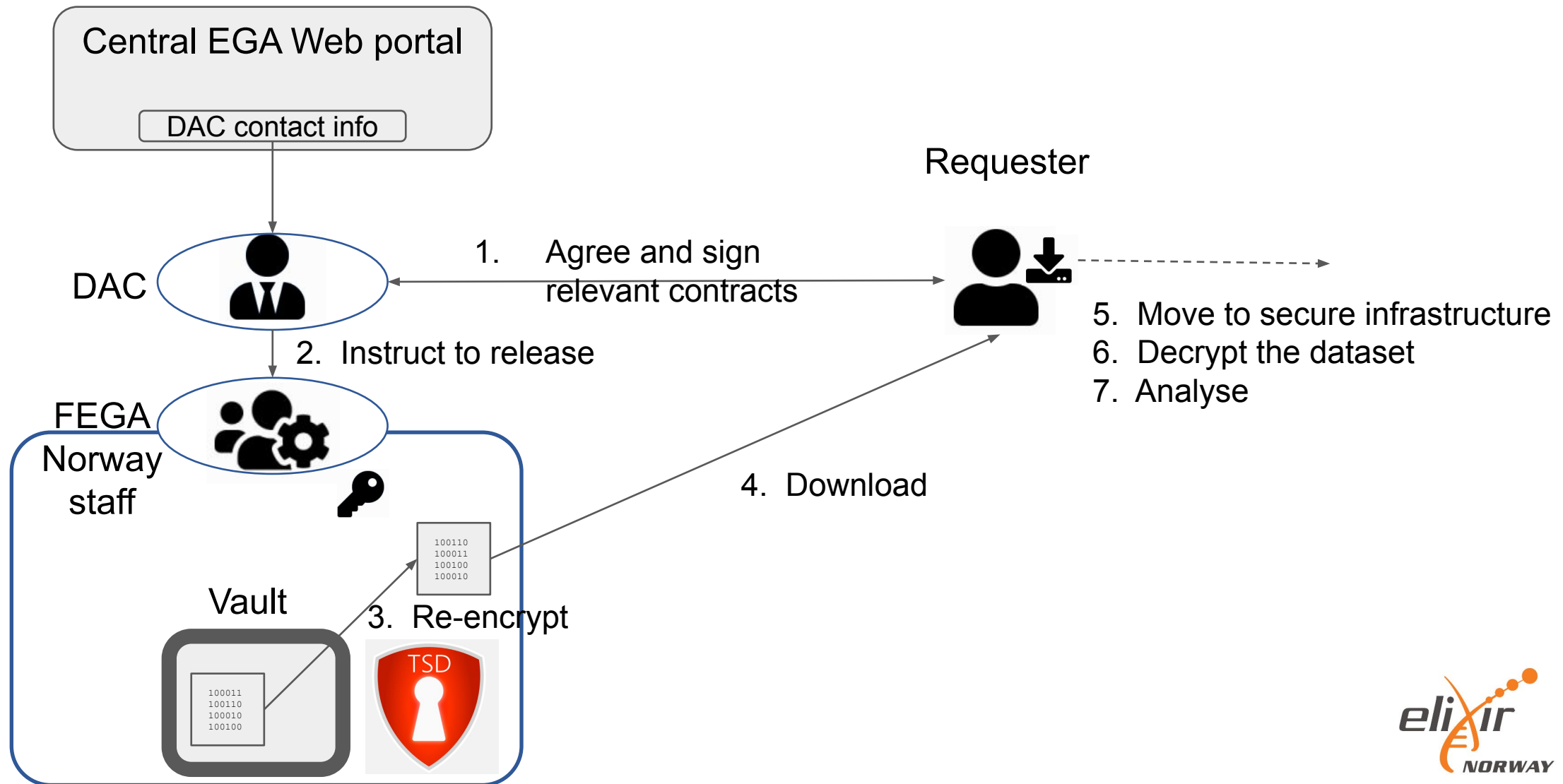


FEGA Norway and Dataflows

Data flow and data control - part I



Data flow and data control - part II



Controlled access and archival

- Dataset existence and description made public available, but not the data itself
- Access to data requires approval by authority controlling the dataset
 - Data Access Committee
- Download and reuse of data may require signed agreements





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Federated EGA Norway node

 **LS LOGIN**

The Federated EGA (European Genome-phenome Archive) is a distributed solution for sharing and exchange of human -omics data across national borders. Federated instance collects metadata of -omics data collections stored in national or regional archives and make them available for search through the main EGA portal.



Searchable



Secure



Shareable



Protecting

The sensitive data stored at Federated EGA instance is encrypted with Crypt4GH - a new standard file container format from the Global Alliance for Genomics and Health (GA4GH), allowing genomic data to remain secure throughout their lifetime, from initial sequencing to sharing with professionals at external organizations.

Strong encryption both in transit and at rest are critical requirements for Genomics England and other genomics in healthcare initiatives.

Augusto Rendon, Crypt4GH implementation leader at Genomics England

Hosted by



UiO : Universitetet i Oslo



Deposit data

Please follow the instructions on how to perform a [submission](#).



Search data

Please follow the instructions on how to perform a [search](#).



Retrieve data

Please follow the instructions on how to perform a [retrieval](#).



Approve access

DAC, please follow the instructions of data [approval](#).

Researcher Guide

This guide describes relevant steps on how to submit datasets to FEGA Norway for further research, data sharing and collaboration. The guide also provides a generic overview of the ethical and legal framework for the process of submission of datasets, including requirements set forth in General Data Protection Regulation (GDPR).

In the planning of submitting datasets to FEGA Norway it is essential that the ethical and legal basis is in place. This means that:

- Submission has to be approved by REK and in compliance with the consent from the study subjects
- The legal basis of using FEGA Norway as repository for your datasets has to be clarified with your own institution (Research support unit and/or Data Protection Officer - DPO). This clarification also includes the need for a Data Protection Impact Assessment (DPIA).

When pursuing the submission process, there are some main steps to be aware of:

Data Processing Agreement between your institution and UiO as the FEGA Norway Service provider

- Establish or document that a Data Processing Agreement (DPA) between your institution and UiO as the host for FEGA Norway Service are in place. FEGA Norway provides a generic template for a Data Processing Agreement (DPA) available [here](#).
- Your Research Support Unit or DPO will help you with the DPA if needed.
- Also remember to file internally a signed copy of the DPA related to your project containing sensitive data, using the standard policy for registering documents in your institution.

Federated EGA Norway node

Submission

This page documents the practical steps to upload data files and meta-data describing your dataset. Before an actual submission you should send us an email at fega-norway-support@elixir.no expressing your interest to submit a dataset to Federated EGA Norway, and you will receive detailed instructions to guide you through the submission process.

Before you start, please, make sure that you have all the required software installed. All the required tools are open-source and developed by Elixir developers. Please, avoid using any third-party tools that are not listed on this page.



[Encryption tool](#)



[File manager](#)



3. Encryption

In order to deposit your data, it must be encrypted first with crypt4gh tool.

The [public key](#) of our Federated EGA Norway service should be downloaded first. Then your own key-pair should be generated.

Finally, the encryption can be performed.

2. Registering

You will need to obtain a Central EGA account prepared for submission to our Federated EGA Norway node. This we will assist you with once you initiate your submission process with our helpdesk (fega-norway-support@elixir.no).

You will also need an Life Science login (a.k.a. ELIXIR AAI) identity to submit data to the Federated EGA Norway node. If you don't have one already, you can easily associate your home institution identity from FEIDE (or other user supported identities) to a LS Login (ELIXIR AAI) user profile during first login, see the login button on our [front page](#).

If you have any questions regarding identities/accounts needed for FEGA Norway, please contact the [FEGA Norway helpdesk](#).

```
1 curl https://ega.elixir.no/ega.pub.pem > ega.pub.pem
2
3 crypt4gh generate -n <key name>
4
5 crypt4gh encrypt -f <file to encrypt> \
6   -s <key name>.sec.pem \
7   -p ega.pub.pem
```

encrypt.sh hosted with ❤ by GitHub

[view raw](#)

The European Genome-phenome Archive (EGA) is a service for permanent archiving and sharing of personally identifiable genetic, phenotypic, and clinical data generated for the purposes of biomedical research projects or in the context of research-focused healthcare systems.

I want to...



Open Submissions

CREATE A SUBMISSION +

● owner | ● collaborator | ○ waiting for approval



First try



second try



The real submission



Test-15082022



Test-300822-fresh-after-failed-add-run



Test3



Test20

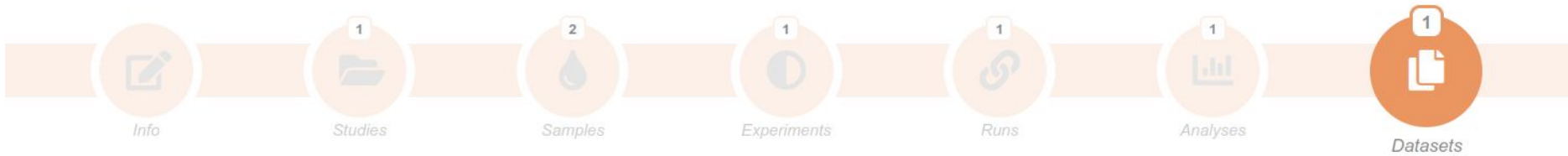
Test-300822-fresh-afther-f...

open

COLLABORATORS

DELETE

FINALISE



Register Dataset

ADD DATASET

Currently registered datasets for this submission

	☐	Status		Title	Types	DAC	No. Runs	No. Analyses	Updated
	☐		7	Demo-Des-2022 Dataset	Transcriptome profiling by high-	EGAC00000000011	1	1	02/12/2022

1 datasets

[Datasets](#) →  EGAD50000000391

Small RNA sequencing of endometrial cancer patients with samples collected prior to diagnosis and controls

This dataset contains unpaired FASTQ files of 316 endometrial cancer cases and 316 matched controls representing circulating RNAs. RNA count files are provided as the output of sncRNA pipeline and represent 12 RNA types (isomiR, lncRNA, precursor miRNA, miRNA, miscRNA, mRNA, piRNA, scaRNA, snoRNA, snRNA, tRF, and tRNA). We also provide metadata of the samples.

 16/04/2024  632 samples  DAC: **EGAC50000000192**  Technology: Illumina NovaSeq 6000

Access Policy

1 Study

645 Files (405.3 GB)

 Metadata Request Access **HMB** **COL** **IRB** **TS** **PS** **IS**

Norwegian Institute of Public Health – Cancer Registry of Norway Data Access Policy for JanusRNA transcriptomics datasets archived in Federated EGA Norway

1. Processing of access requests

Data access requests to the JanusRNA transcriptomics datasets are processed according to the detailed descriptions available from the JanusRNA website:

- <https://www.kreftregisteret.no/en/Research/Projects/Identification-of-early-cancer-biomarkers/>
- Contact details to the JanusRNA Data Access Committee (defined below), as well as required information needed and how to provide it is specified in this website.

> [Int J Cancer](#). 2024 Sep 1;155(5):946-956. doi: 10.1002/ijc.3

Differential levels of circulating endometrial cancer diagnosis

Sina Rostami^{1 2}, Trine B Rounge^{1 3}, Luca Pestarino^{1 4},
Renée Turzanski Fortner^{1 7}, Øystein Ariansen Haaland⁸,
Tone Bjørge^{8 10}, Hilde Langseth^{1 11}

Affiliations + expand

PMID: 38733362 DOI: 10.1002/ijc.34951

Abstract

Endometrial cancer (EC) is one of the most common female routine screening strategy for early detection. An altered at (miRNAs) and other RNA classes have the potential as early circulating RNA levels using small RNA sequencing, targetin nucleotides, in EC patients with samples collected prior to d controls. The analysis included 316 cases with samples colle

ETHICS STATEMENT

The study was approved by Norwegian Regional Committee for Medical and Health Research Ethics (REC no: 19892). The JSB donors have given broad consent for the use of the samples in cancer research.¹⁷

Open Research

DATA AVAILABILITY STATEMENT

Accession number

RNA sequencing data generated in this study have been deposited in the database Federated EGA Norway (FFGA Norway) under accession code EGAD50000000391 (<https://ega-archive.org/dataset/EGAD50000000391>). The data are available under restricted access due to the sensitive nature of data derived from human biological material. The data are available on request provided that the processing has legal basis, and otherwise meets the conditions set out in applicable law. The data may only be used for cancer research purposes, and the recipient must have ethical approval from the Norwegian Regional Committee for Medical and Health Research Ethics (REC). Access can be obtained by following the procedure described here: [Access to ata \(krefregisteret.no\)](https://krefregisteret.no). A data Access committee is established at The Norwegian Institute of Public Health, and will evaluate applications for data access. Requests can also be directed to Hilde Langseth, hl@krefregisteret.no. Script for the differential abundance analysis can be accessed from Github (<https://github.com/CancerRegistryOfNorway/ec-rna>) and (<https://github.com/Rounge-lab/ec-rna>). Further information is available from the corresponding authors.

Supporting Information

REFERENCES

DAC Portal

Welcome to the DAC Portal documentation!

If you are involved in governance or legal aspects, technical or operational aspects, or serving as a data steward, this page will be helpful for you. By exploring these materials, you can define your own Data Access Committee (DAC) and policies, understand the minimal requirements for a DAC and a policy object, and comprehend how the EGA data access requests are managed.

DAC Portal Index



Setting up your account

1. Register yourself as an [EGA user](#).
2. The Helpdesk team will validate your account (this could take up to 48 hours). After validation, you will receive an email with a link to verify your email - Make sure you click on the link to verify your account!
 - If you don't receive the email, please check your spam folder.
3. Once your account is active you can login to the [DAC Portal](#).

FAIR Principles

Make your data:

- **F**indable
- **A**ccessible
- **I**nteroperable
- **R**eusable

Findable

- Describe metadata
- Persistent identifiers

Accessible

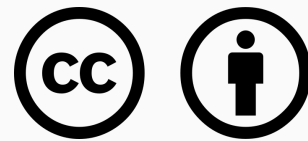
- Determining what to share
- Participant consent and risk management
- Access status

Interoperable

- XML standards
 - Data
 - Documentation
- CDISC

Reusable

- Rights and licence models
- Permitted and non-permitted use



Thank you

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fega-norway-support@elixir.no

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