Federated EGA: A global network for discovery and access of sensitive human data

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14th ICHG, 22-26 February 2023, Cape Town, South Africa

CRG Centre for Genomic Regulation

EMBL-EBI

Abstract

With increasingly strict regulations for managing sensitive human omics and healthcare-derived data, solutions are required to ensure research and clinical data can be accessed across national borders. Safely sharing sensitive data is vital for data reuse to support biomedical research and personalised medicine programs. The Federated European Genome-phenome Archive (FEGA) provides a data sharing solution of infrastructure and governance frameworks to support discovery of and secure access to human data globally, while respecting national data protection regulations. Prompted by European initiatives such as the 1+ Million Genomes and European Health Data Space, the FEGA was officially launched in 2022 with a network of nodes in the UK, Spain, Norway, Sweden, Finland, and Germany. The next phase of FEGA will build upon these early successes to expand data sharing both within and outside of Europe. Accelerating this expansion can be achieved through collaboration with initiatives already working towards human data sharing, for example: the European Genome Data Infrastructure (GDI), Data Science for Health Discovery and Innovation in Africa (DS-I Africa), and Australian BioCommons. Ultimately, the FEGA vision is to build a global, interoperable discovery and access network of human data resources, to accelerate disease research and understand and improve human health.

The European Genome-phenome Archive (EGA) securely shares sensitive human data

The 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** [1]. Data archived at the EGA were collected from individuals whose consent agreements authorise data release only for specific research use to *bona fide* researchers.

African research represented in EGA

Percent of EGA studies with samples from African populations: **1.1%**

Countries represented in these studies →

Datasets in EGA managed by H3Africa: **23**

H3Africa Human Heredity & Health in Africa

**72,577** → Samples from African individuals archived at EGA
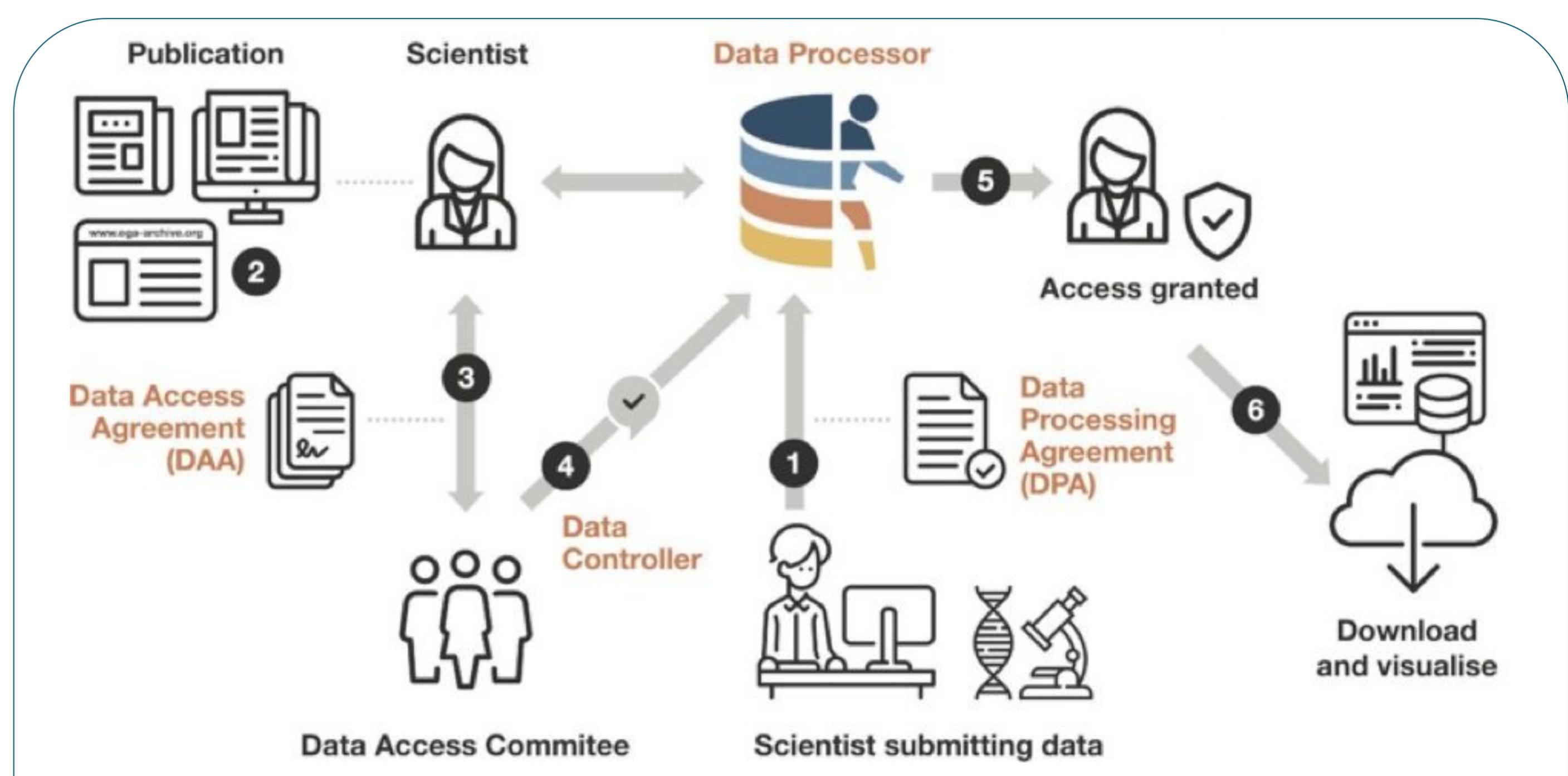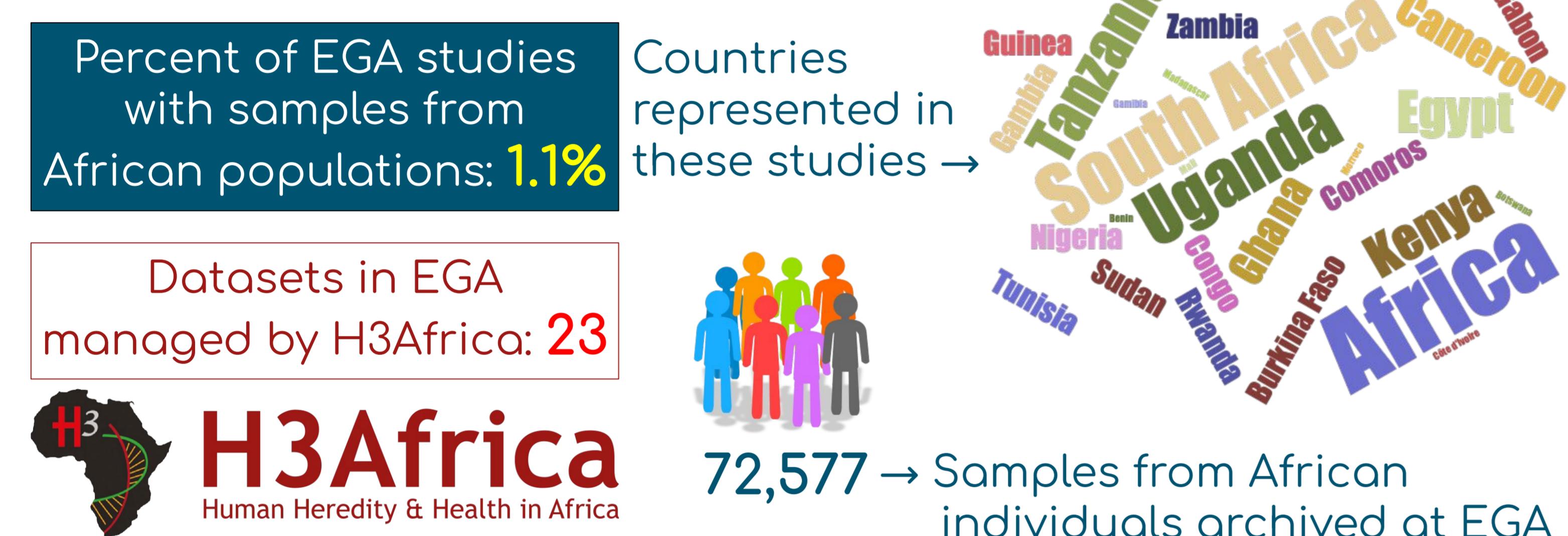
Figure 1: EGA facilitates the submission, discovery, access, and distribution of sensitive human data following strict protocols. Researcher submits controlled access human data to EGA after signing a Data Processing Agreement (1). EGA processes, archives, and releases the dataset to be findable. Another researcher discovers data of interest at the EGA (2). They contact the Data Access Committee (DAC) for the data of interest and agree to the terms of data reuse by signing a Data Access Agreement (3). The DAC informs EGA that access is approved (4). The EGA grants access to the researcher (5) who can then download and visualise the data (6).

Federated EGA as a global network for sensitive data discovery and access

Federated European Genome-phenome Archive

Vision: A global resource for discovery and access of sensitive human omics and associated data consented for secondary use, through a network of national human data repositories to accelerate disease research and improve human health.

Value for Researchers
- Common standards and interfaces → *interoperability*
- Common phenotypic & clinical data models → *(meta)data harmonisation*
- Federated user identity → *simpler, faster data access*

Value for Federated EGA nodes
- Peer collaboration network of expertise & knowledge
- Increased data reuse via FEGA discovery network
- Access to common standard operating procedures
- Collaboration on technical implementations
- Increased interoperability with similar initiatives
- Access to shared training and outreach materials

How to join Federated EGA Network

Scan to learn more
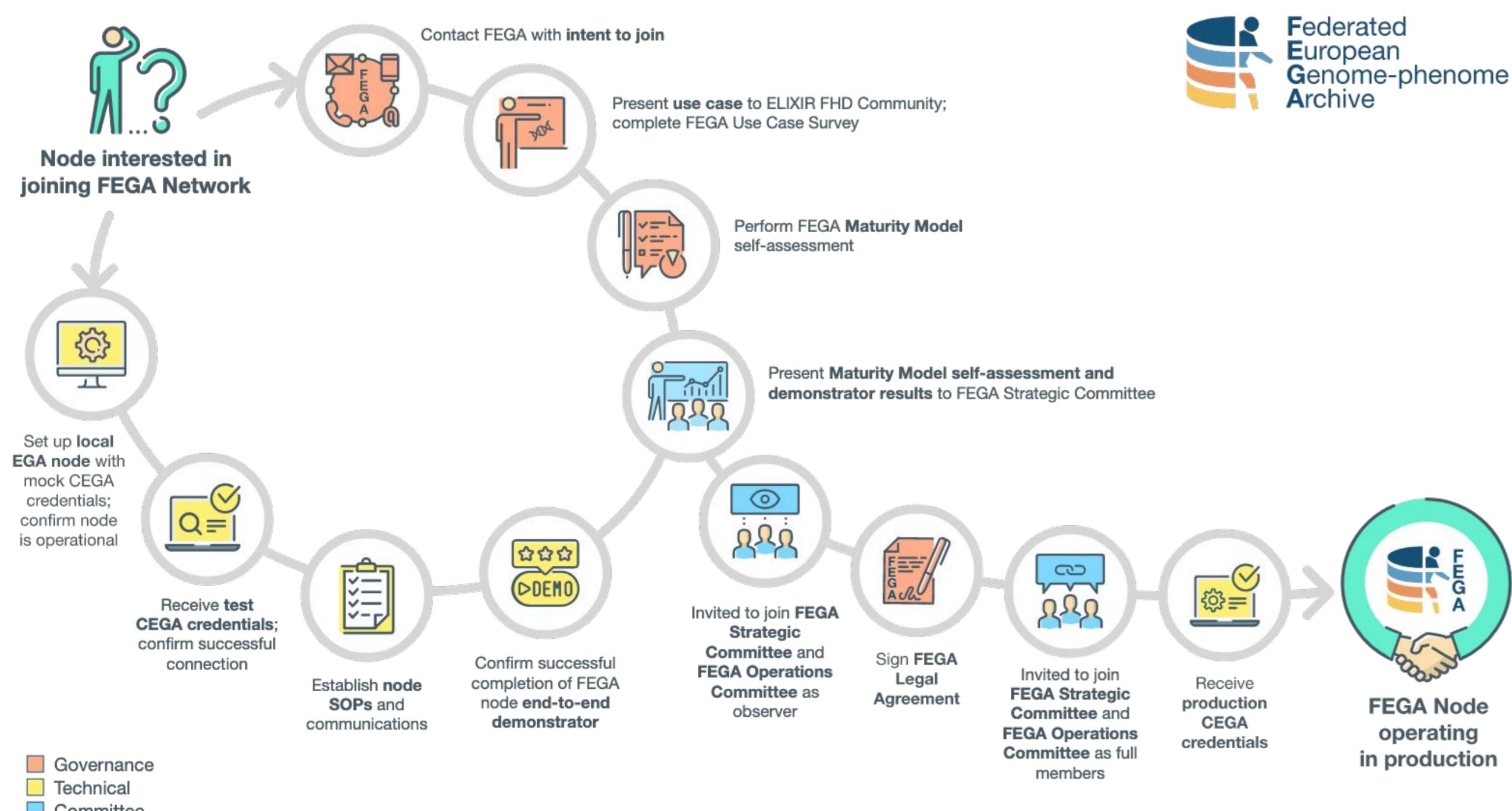
about Federated EGA!

Federated EGA in 2023

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

Vision is a federated **worldwide** network for sensitive human data discovery and access.

References & Resources
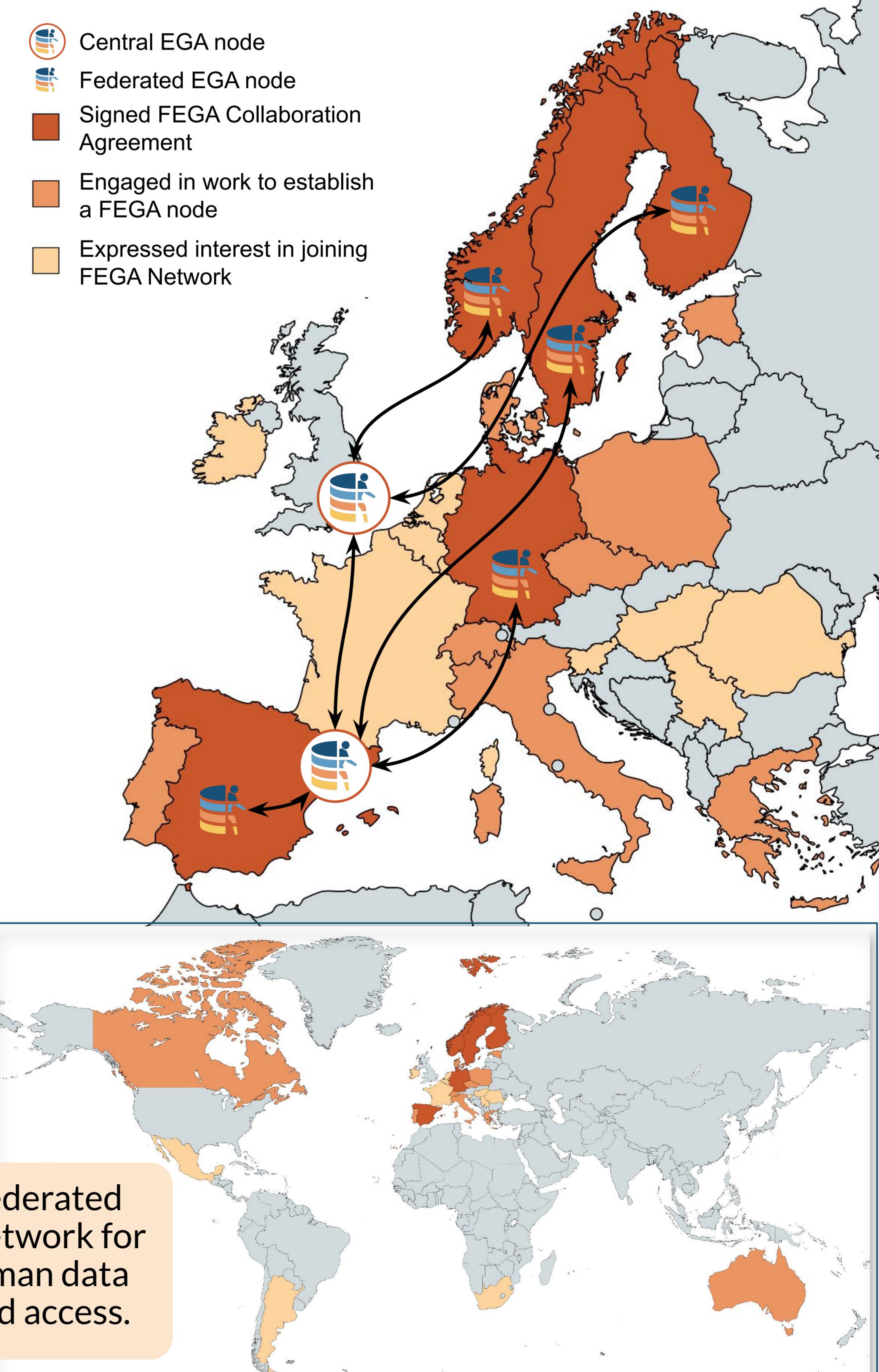
- [1] https://doi.org/10.1093/nar/gkab1059
- Establishing a FEGA Node: https://ega-archive.github.io/FEGA-onboarding/
- FEGA updates @ ELIXIR Federated Human Data Community: https://elixir-europe.org/communities/human-data

elixir