[Federated] EGA

Providing global discovery and access for sensitive human data

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EUROPEAN GENOME-PHENOME ARCHIVE

EMBL-EBI

CRG Centre for Genomic Regulation

BSC Barcelona Supercomputing Center
Centro Nacional de Supercomputación

Sharing sensitive data key to enable science & health

Exposure of personal or sensitive data is **potentially harmful**	Individuals have the **right to protection** of their personal data	Governments pass legislation that **codifies data protection rights**	Support aims of research & health care initiatives

EGA manages sensitive human data

EUROPEAN GENOME-PHENOME ARCHIVE

Mission: 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

Drive development of and implement community standards for supporting FAIR data sharing

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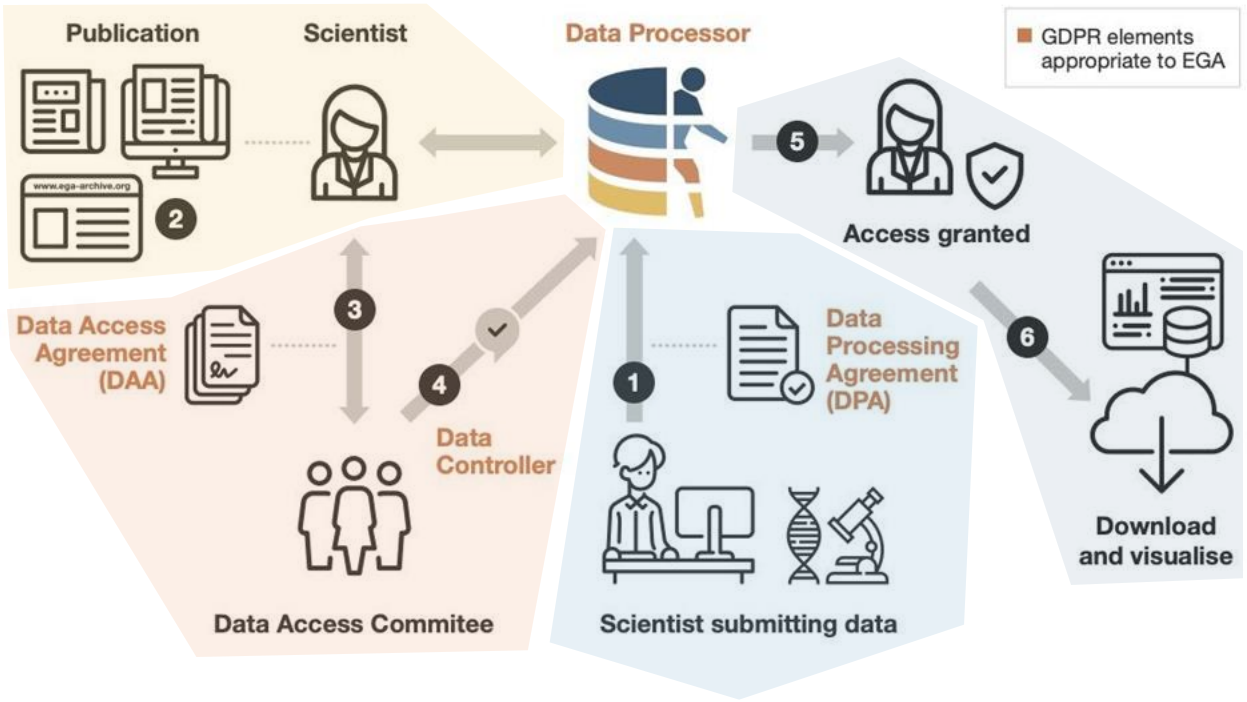
Global Alliance for Genomics & Health
Collaborate. Innovate. Accelerate.

2008: EGA launched at EMBL-EBI

2013: CRG & EMBL-EBI enter formal collaboration to co-manage EGA

EGA data access model



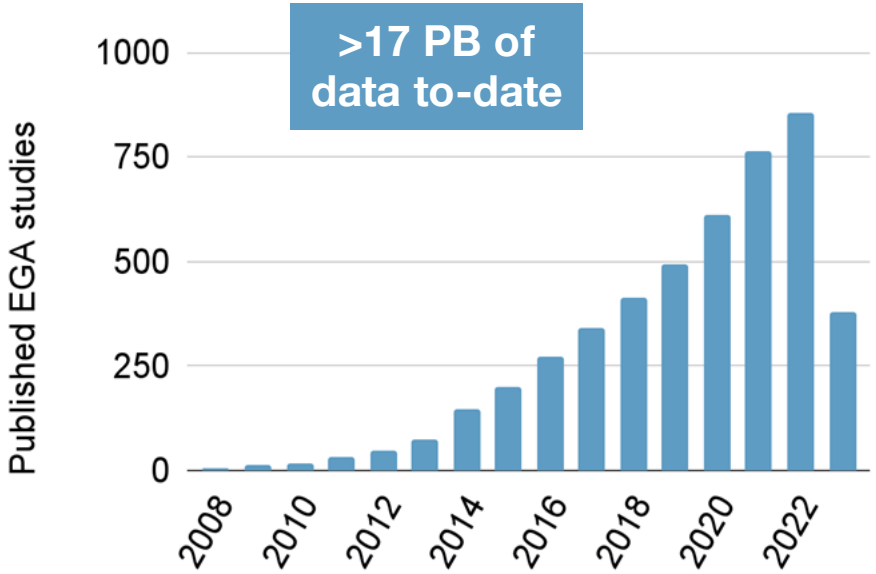
Data submission

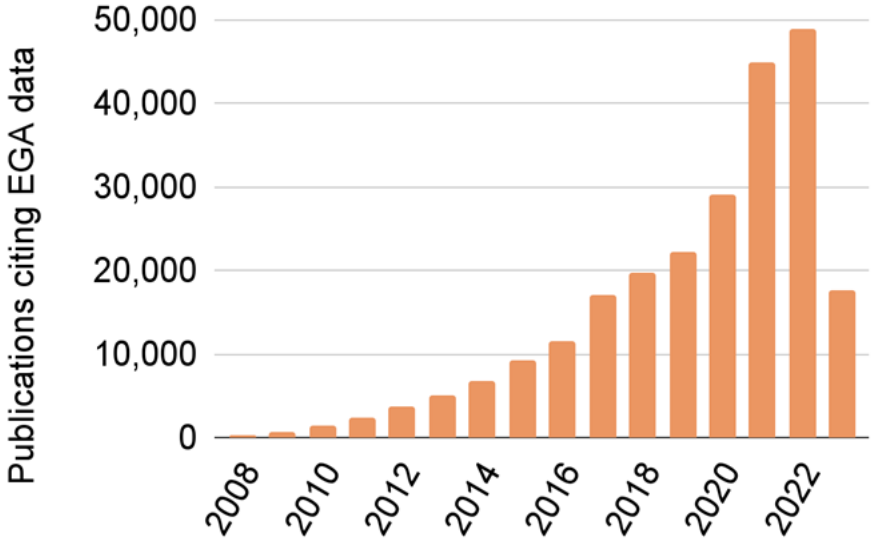
Data discovery

Data access

Data distribution

EGA grows and remains key to life science research





Last Updated : June 20 2023

Impact of EGA in personalised medicine – Common diseases

EGA Studies:

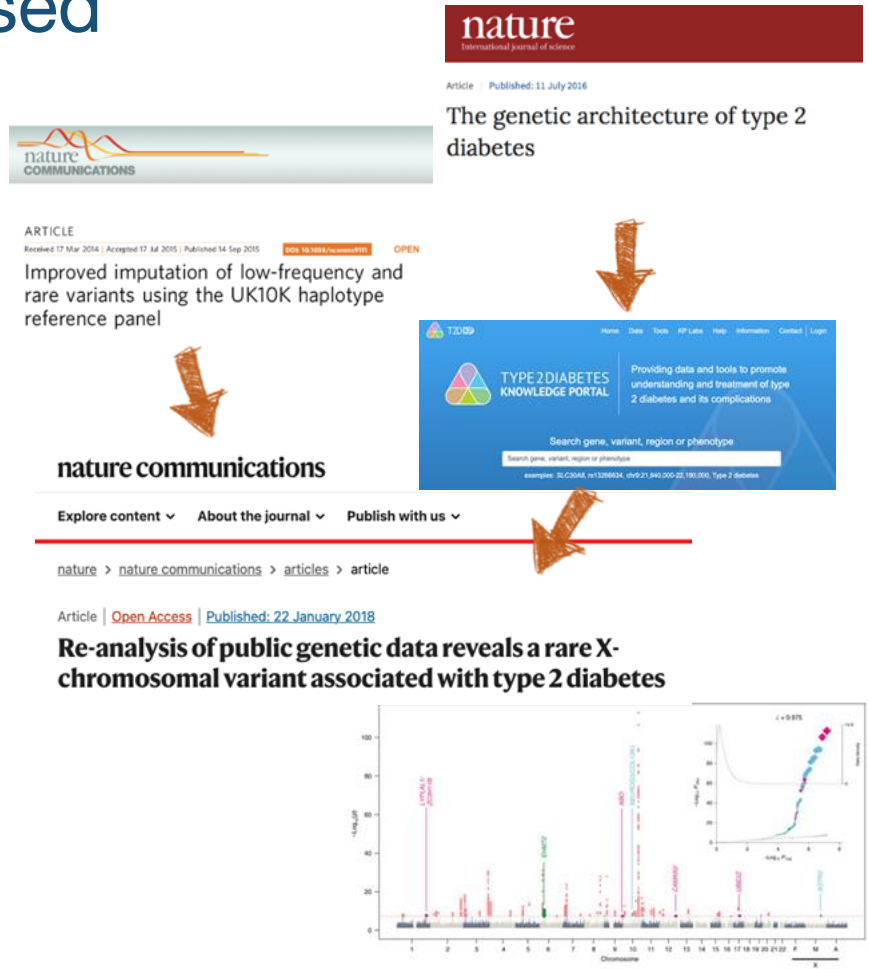
- UK10K (EGAS00001000713)
- WGS GoT2D (EGAS00001001459)
- WES GoT2D (EGAS00001001460)

Revision and reanalysis of existing genetic data by applying more powerful analytic techniques and resources generated.

A total of 70,127 subjects (70KforT2D) were retained for downstream analysis

Up to 7 loci were identified that were not previously reported as associated with T2D. Providing more candidate causal variants.

refs: Nature Comms (2015), Nature (2016), Nature Comms (2018)



European 1+MG initiative sets vision for data sharing

Towards access to at least 1 million sequenced genomes in the EU by 2022

B1MG

Beyond One Million Genomes Project

European Genomic Data Infrastructure

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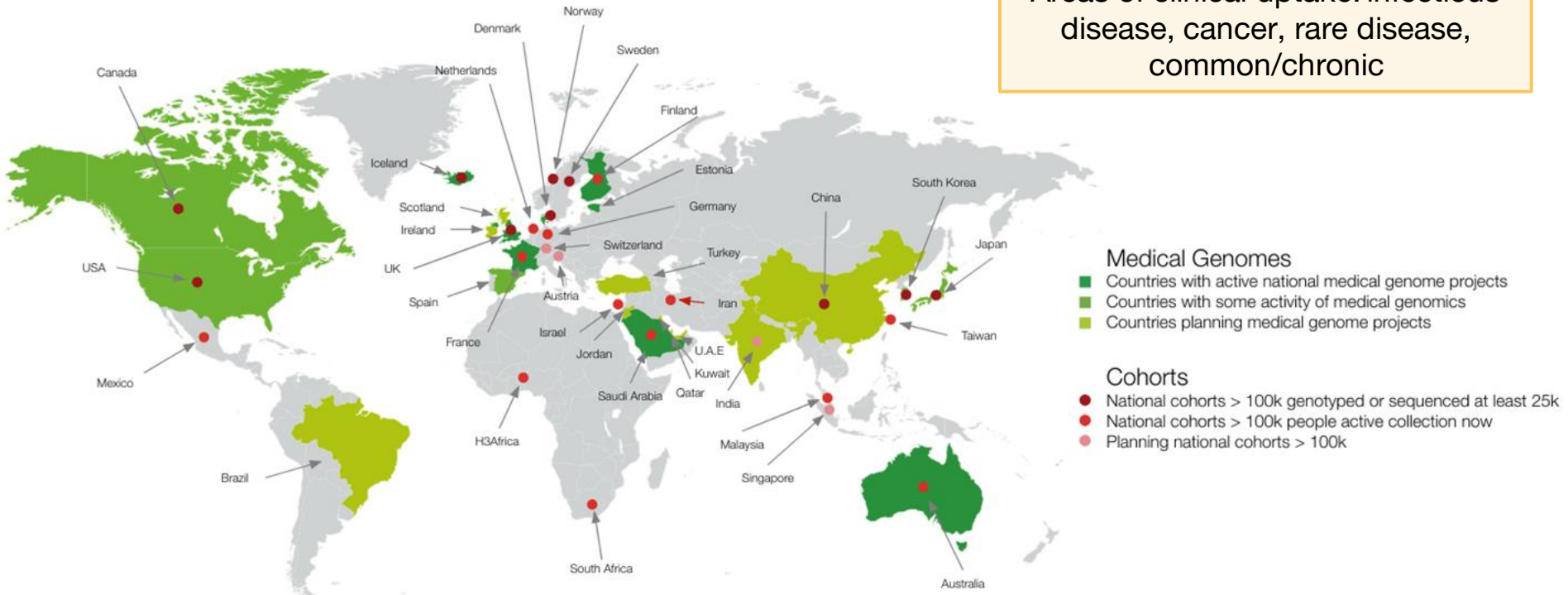
ELSI GA4GH API

Federated EGA

More genomics data generated in healthcare context

Areas of clinical uptake: infectious disease, cancer, rare disease, common/chronic

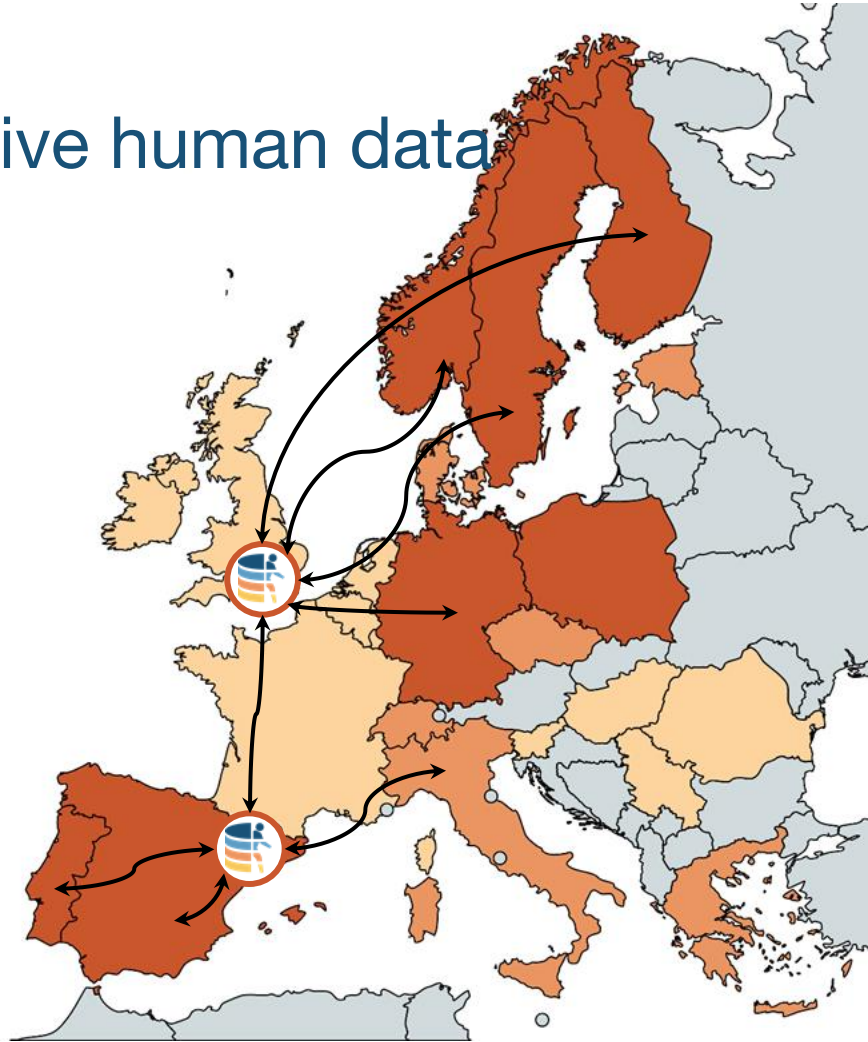


Federated EGA collaboration officially launched in September 2022

Federated
European
Genome-phenome
Archive

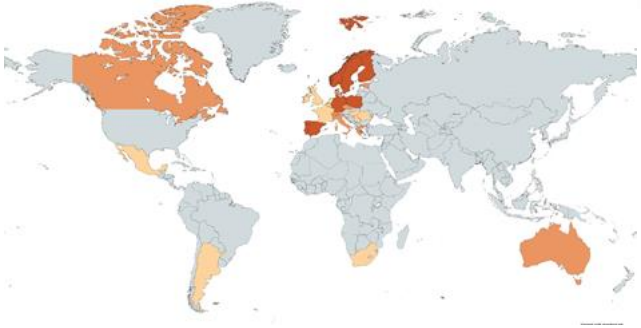
Federated EGA:
discovery & access for sensitive human data

Federated 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.

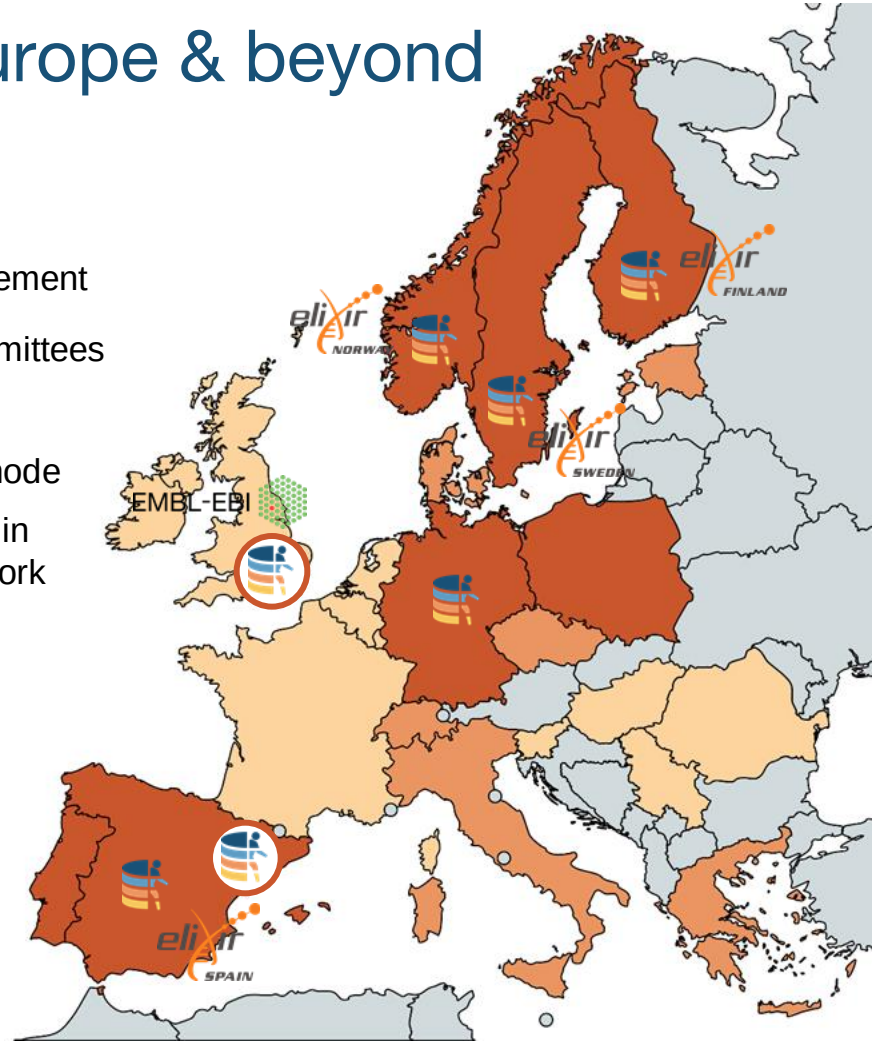


FEGA engagement across Europe & beyond

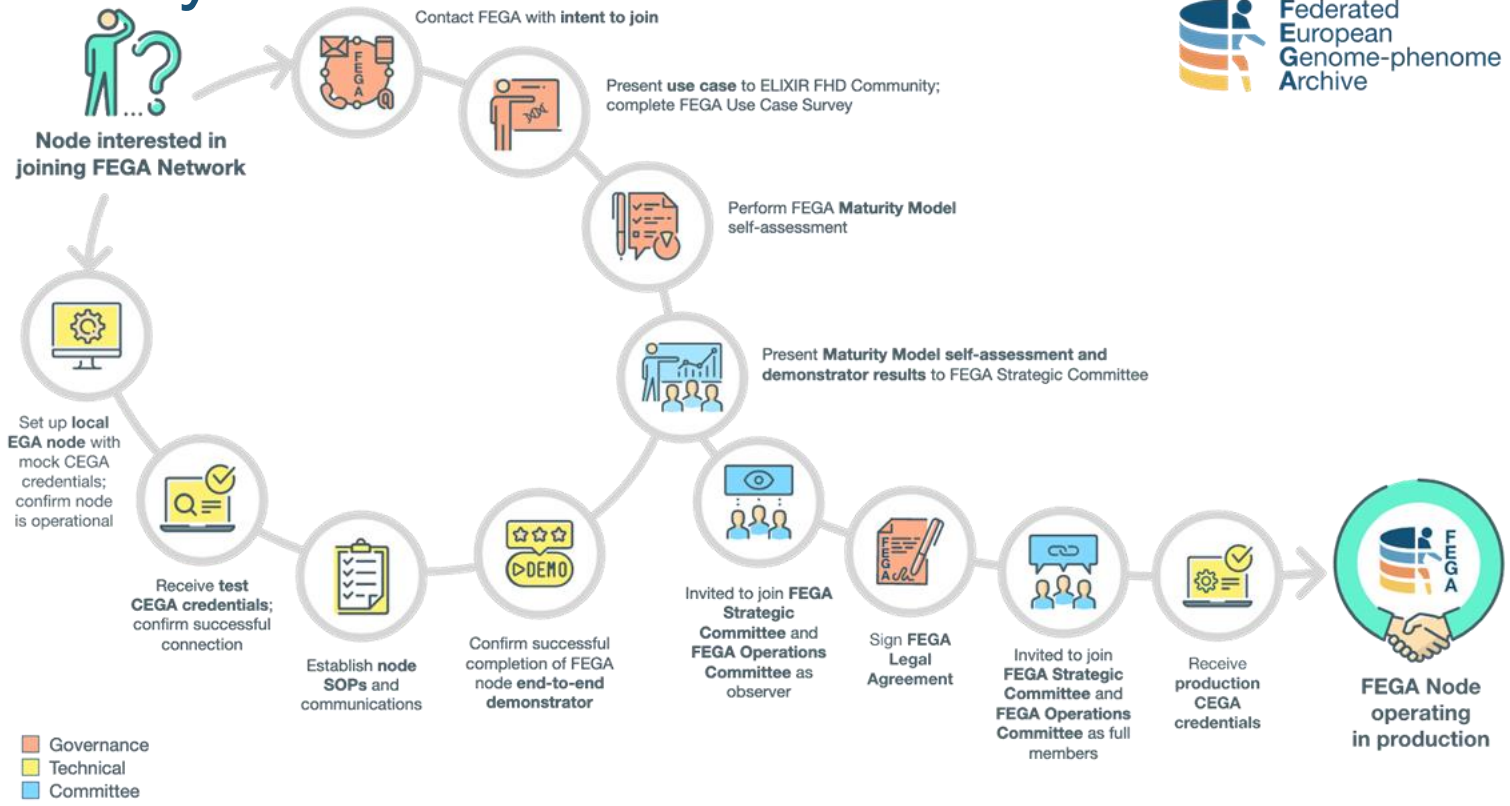
>24 nodes engaged and counting!



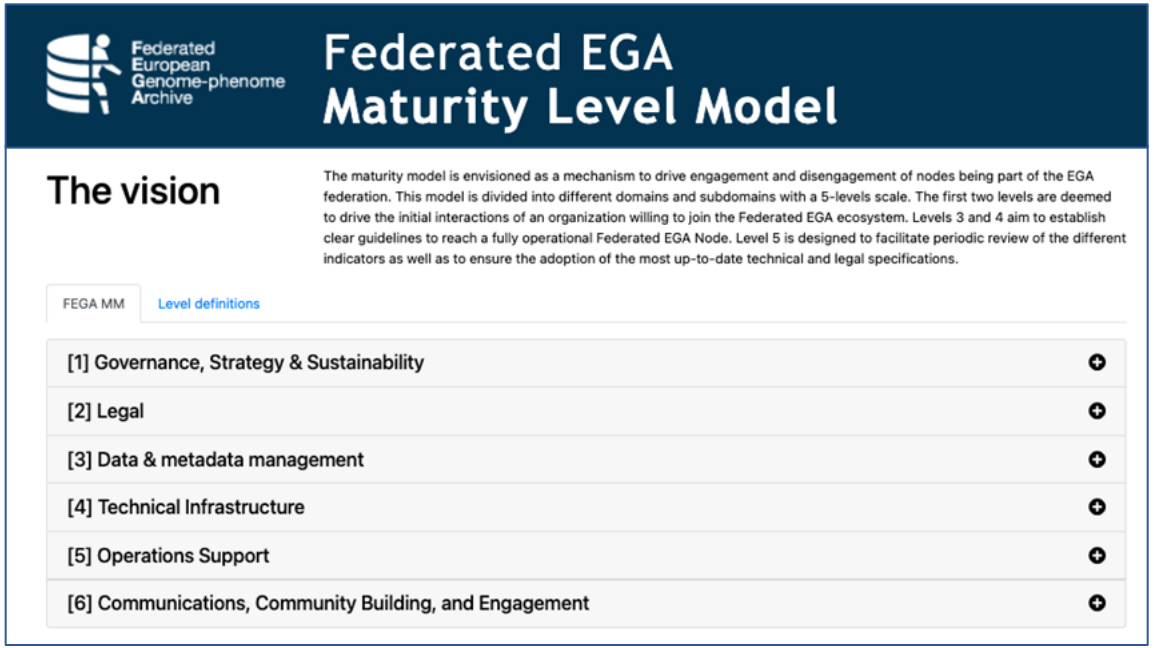
- Central EGA
- Signed FEGA Collaboration Agreement
- Joined FEGA Committees
- Engaged in work to establish a FEGA node
- Expressed interest in joining FEGA Network



Joining FEGA network follows established pathway



FEGA Maturity Model enables self-assessment



Align with other Maturity Models

B1MG

HEALTHYCLOUD
Health Research & Innovation Cloud

FAIRplus

Global Alliance for Genomics & Health
Collaborate. Innovate. Accelerate.

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https://inab.github.io/fega-mm/

Guidance for nodes considering joining FEGA

https://ega-archive.github.io/FEGA-onboarding/

What's next for EGA and Federated EGA?

- ➔ Build on human data sharing knowledge & experiences of experts across Europe
- ➔ Accelerate additional national nodes joining Federated EGA
- ➔ Continue advocating for community standards via Driver Projects and ELIXIR::GA4GH Strategic Partnership
- ➔ Support transnational access to human data across Europe & beyond via ELIXIR-coordinated initiatives/projects e.g. 1+MG, B1MG, GDI

Acknowledgements: Federated EGA

Thank you!

Questions?

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Additional resources

- EGA: https://ega-archive.org/
- Joining FEGA: https://ega-archive.github.io/FEGA-onboarding/
- GA4GH: https://www.ga4gh.org/
- ELIXIR: https://elixir-europe.org/
- GDI: https://gdi.onemilliongenomes.eu/