

Declaration on linking
genomic databases across borders

1+ Million Genomes

"Towards access to 1 million Genomes
in the EU by 2022"



Delivering cross-border access to genomic database

- Declaration signed on 10 April 2018 during Digital Day 2018
- European Commission's Digital Single Market mid-term review "supporting the establishment of a secure health data infrastructure at EU level, to advance research and personalised medicine".
- A member states driven initiative supported by the European Commission



More member states have joined

- 20 signatory countries
- 8 countries have observer status
BE, CH, DE, DK, FR, IE, NO, PL

EU countries agreed to cooperate in linking genomic data across borders

**THEY
DID IT!**
& more will too



Austria
Bulgaria
Croatia
Cyprus
Czech Republic
Estonia
Finland
Greece
Hungary
Italy
Lithuania
Luxembourg
Malta
Portugal
Slovenia
Spain
Sweden
Netherlands
UK
Latvia



The 1+ Million Genome initiative

- Federated framework that would allow **secure** and **authorised** cross-border access to **genomic** and other **health data** across the EU, supporting **research, health care and prevention**.

Member States of the European Union, the European Economic Area (EEA) and the European Free Trade Association (EFTA)



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- To allow users to search and access the data through a user-friendly and effective data governance structure **building on existing national and European initiatives**.

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The 1+ Million Genome initiative

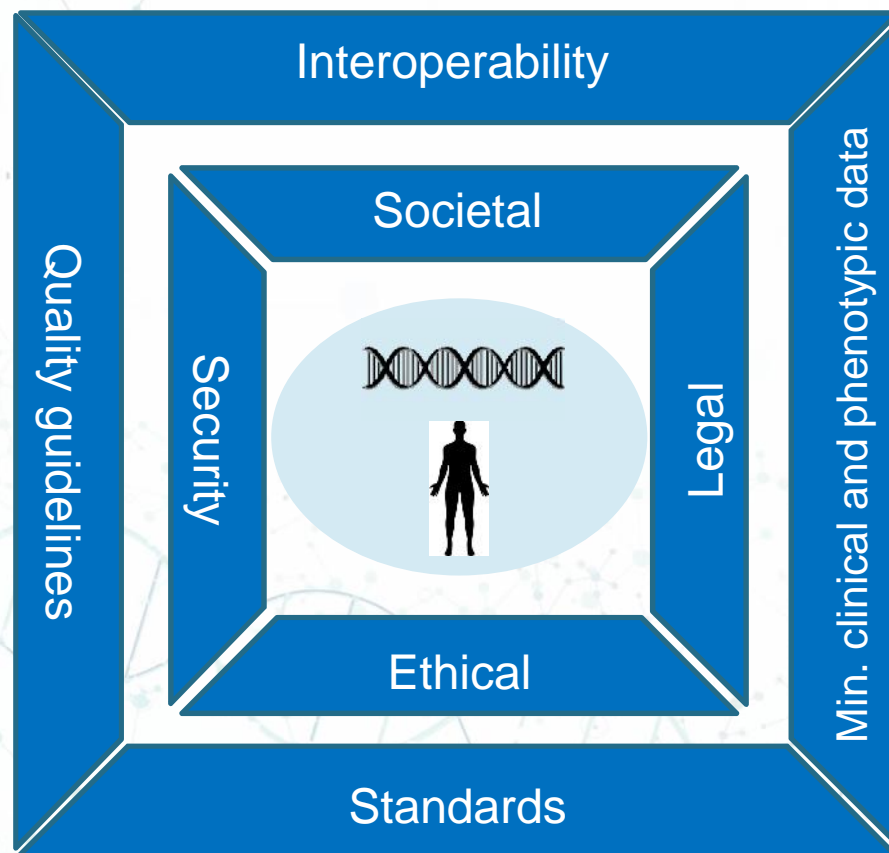
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- To allow users to search and access the data through a user-friendly and effective data governance structure **building on existing national and European initiatives**.
- To ensure that citizens, researchers and health systems in Europe can benefit from the full potential of genomics to **advance targeted health care interventions** leading to better **prevention, early diagnosis and treatment of diseases**

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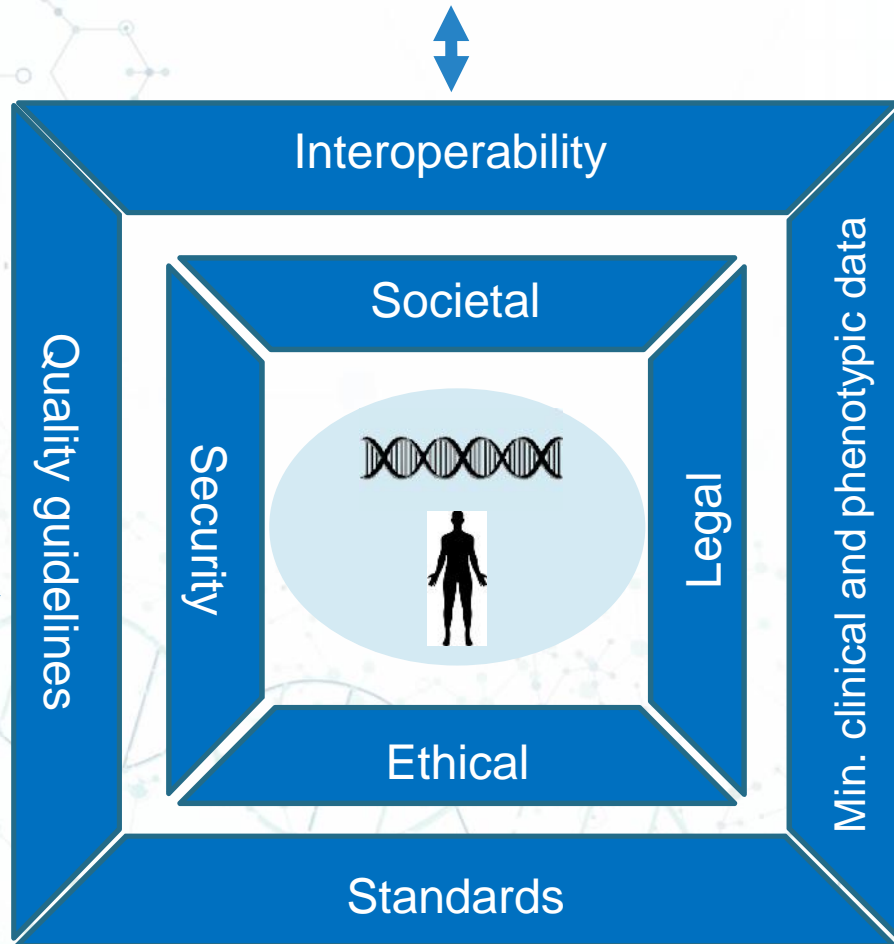
A challenging goal

- The framework - aspects to tackle



Join forces!

National clinical genomics initiatives



Canada-EC Joint Health Data Flagship Collaboration



Current activities

- 10 working groups – link up to expertise/projects/initiatives identify gaps/needs/activities
 - 3 use cases
 - Mapping of current and future genomic initiatives and data
 - Interim governance structure – national mirror groups
- Road map



Interim governance

Steering Committée/Board – signatory MS

Acting as the governing body made up of representatives from MS

Coordinating group

National mirror group



WG-lead/co-lead
Members
Experts
European infrastructures
Groups/initiatives/projects



Creation of working groups

- WG1 Scope, stakeholders and governance
- WG2 Ethical, Legal, and Societal Issues (ELSI)
- WG3 Common standards and min. dataset for clinical and phenotypic data
- WG4 Good sequencing practice
- WG5 Federated, secure, interoperable and privacy-respecting framework and access governance
- WG6 Health economics and outcome research
- WG7 Involvement of the private sector
- WG8 Use case - Rare diseases
- WG9 Use case - Cancer
- WG10 Use case - Populations, Precision prevention, Pharmacogenomics



Thank you!

The declaration can be found here:

<https://ec.europa.eu/digital-single-market/en/european-1-million-genomes-initiative>

