



Implementation and next steps

Genomic Data Infrastructure
European Health Data Space
GAIA-X

Chair: Serena Scollen

02



Genomic Data Infrastructure

What is it, what will it look like?

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Genomic Data Infrastructure

Scale up and Sustainability

B1MG Stakeholders Forum
October 13th 2022



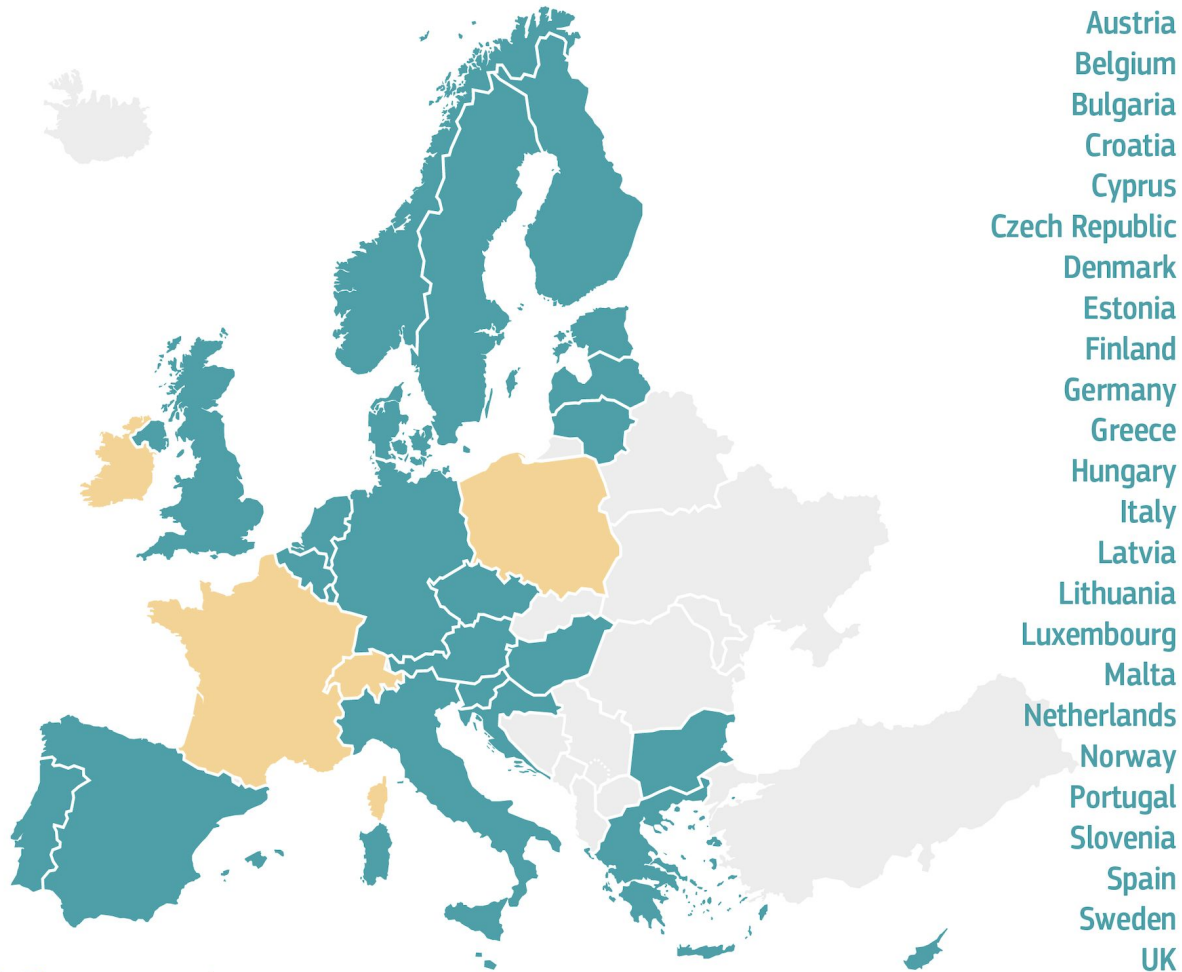
Beyond one Million Genomes

Slido: SF2022

“The 1+ Million Genomes initiative has the potential to improve *disease prevention*, allow for more *personalised treatments* and provide new *impactful research*”

From the 1-million-genome EC web page

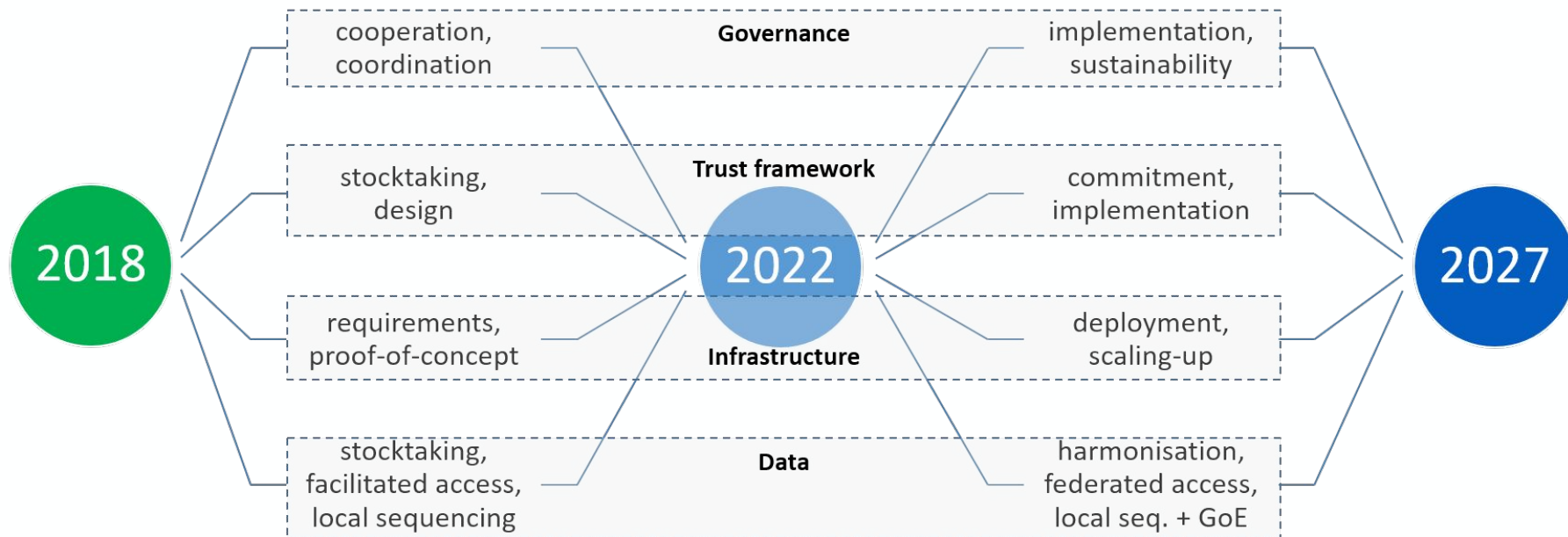
● Observer countries



1+MG Roadmap

design & testing phase

scale-up & sustainability phase



Realising a practice of personalised medicine & health



Long-term strategy: cross-border access to genomic data, implementation of genomics-based health
1+MG Group, National Mirror Groups and Thematic Working Groups
Use Cases Working Groups: cancer, infectious diseases, rare diseases, common complex diseases, industry
Genome of Europe (GoE)

Design and testing



Maturity Model

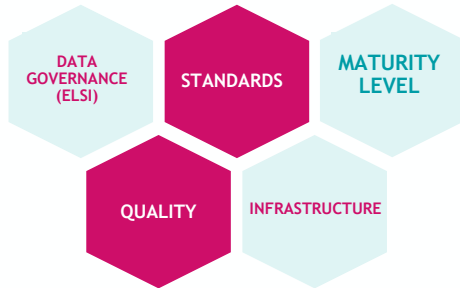
ELSI recommendations and toolkits

Technical recommendations and guidelines

European genomics dashboard

1+MG Trust Framework

- Data governance
- Standards and Quality
- Infrastructure
- Maturity model



Scale up and sustainability

Sustainable cross-border secured access to genomic and health data

Genomic Data Infrastructure

- Governance, legal entity, business plan
- Data infrastructure deployment and operation (20 MS)
- Innovative applications and solutions
 - GoE, Cancer, Infectious diseases, Federated learning, ..

GDI Structure

ELIXIR

Coordination and Support: Project mobilisation, monitoring and control. Communications, Stakeholders, Genome of Europe coordination

Pillar 1 - Long-term sustainability LU, ES

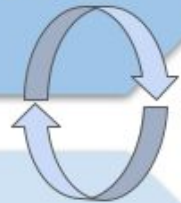
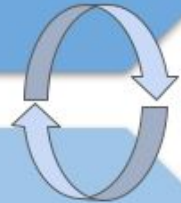
Provide the 1+MG Group and committed countries with models and frameworks on which they can agree to develop a sustainable, European genomics data infrastructure to support better healthcare and research

Pillar 2 - 1+MG infrastructure deployment FI, SE

Incrementally increase the interoperability of technical services and readiness levels of European, national and regional data hubs

Pillar 3 - Application and innovation solutions ES, BE, DE

Develop the technical solutions required to tackle disease scenarios.



Pillar I Long Term Sustainability



Governance Model

What needs to be sustained and what structures have to be in place to operate 1+MG and its Data Infrastructure beyond 2026

Legal entity

Which is the most appropriate legal instrument to enable it

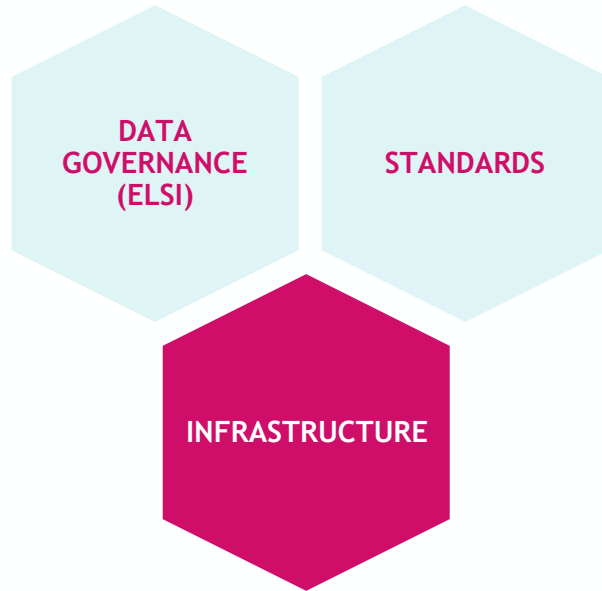
Business Model

Which is the cost and how it will be funded

Member States representatives direct involvement is crucial to ensure:

- Adoption
- Sustainability

Pillar II 1+MG infrastructure deployment & operations



- **Deployment of 1+MG national nodes**
 - **Onboarding:** Design and testing phase (1+MG engagement)
 - **Deployment:** National node fully operational
 - **Operational:** National nodes interconnected

National Nodes	2024	2026
Operational	6	15
Deployment	9	18
Onboarding	9	20



Pillar II 1+MG infrastructure deployment & operations

- Based on 1+MG Trust framework
 - Supported community standards
 - Open source reference implementations
 - Co-owned, co-developed, co-operated by MS selected organisations
 - Security, data protection, ELSI by design
 - Cross border data access PoCs based on real use cases

Standards

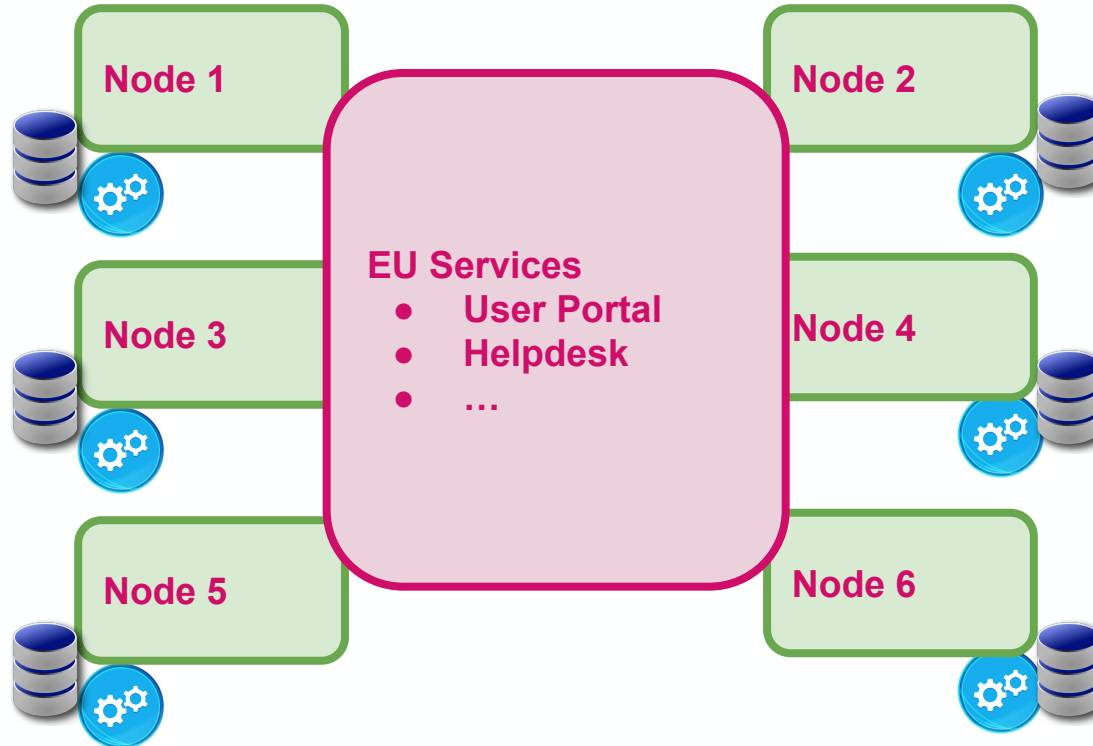
GA4GH standards



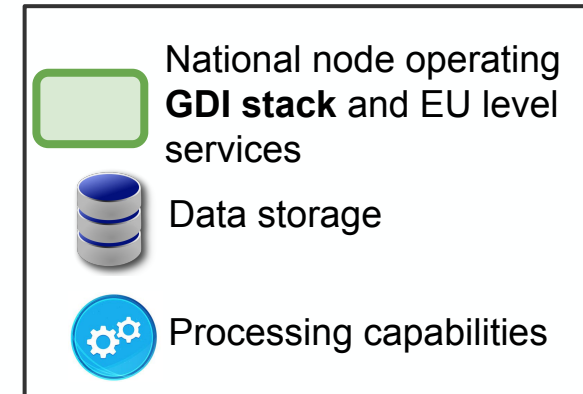
Pillar II 1+MG infrastructure deployment and operations

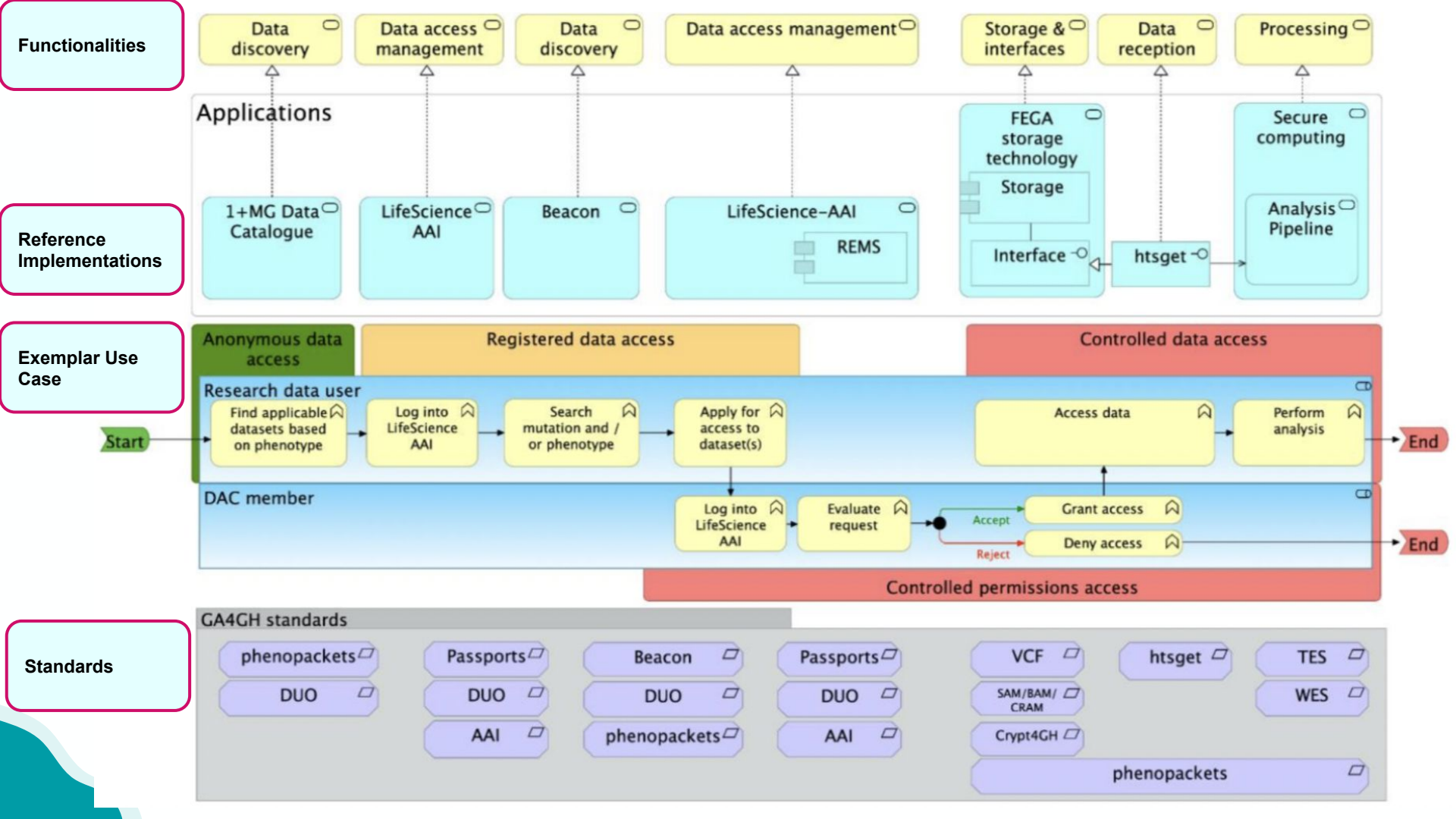
- **European level services**
 - User portal (including data catalogue)
 - Data discovery services
 - Helpdesk
- **Data Management**
 - “Real” synthetic data and metadata
 - Data management support to Nodes
- **Technical outreach**
 - Technical capacity building

Pillar II 1+MG infrastructure deployment and operations



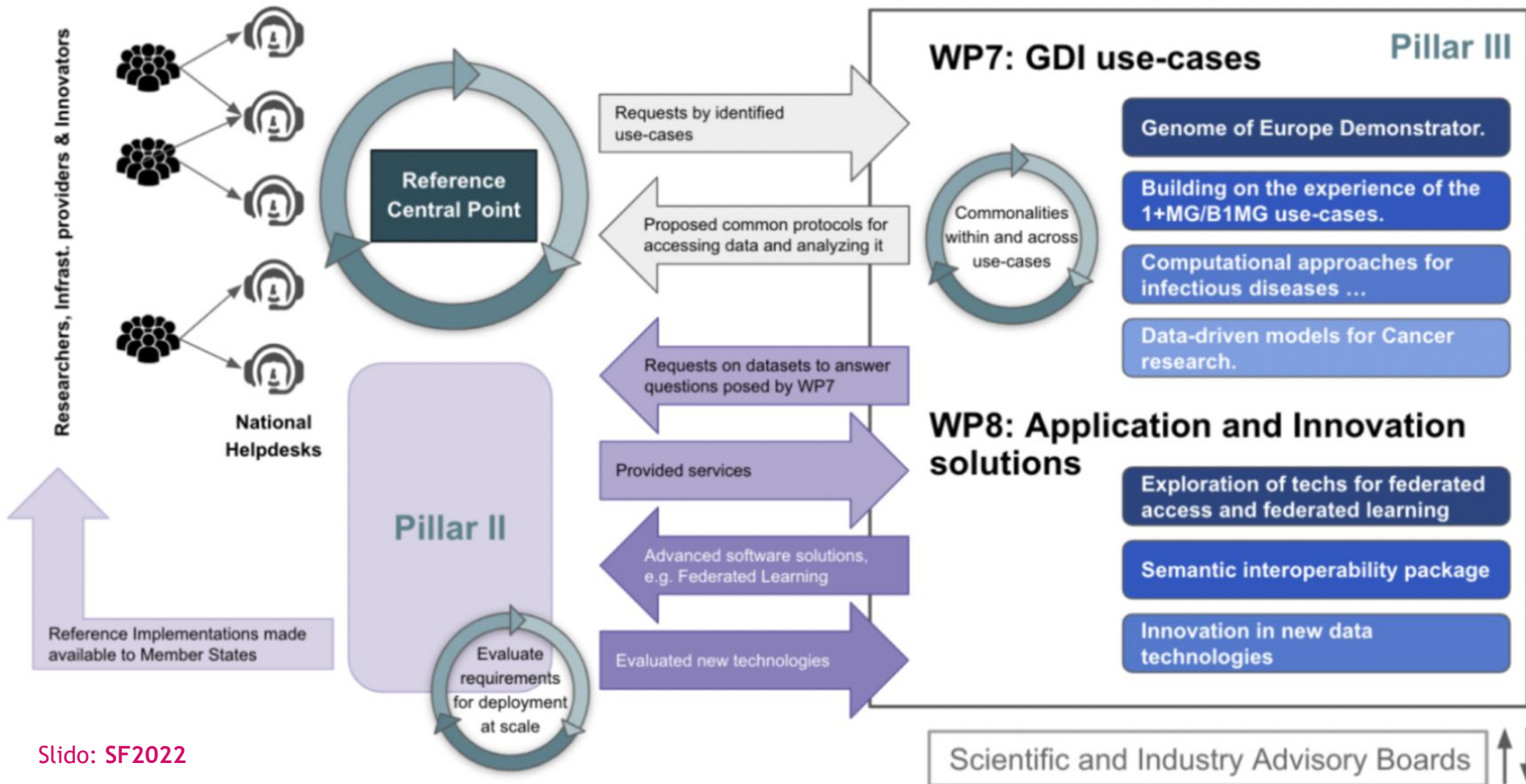
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Pillar III Application and innovation solutions

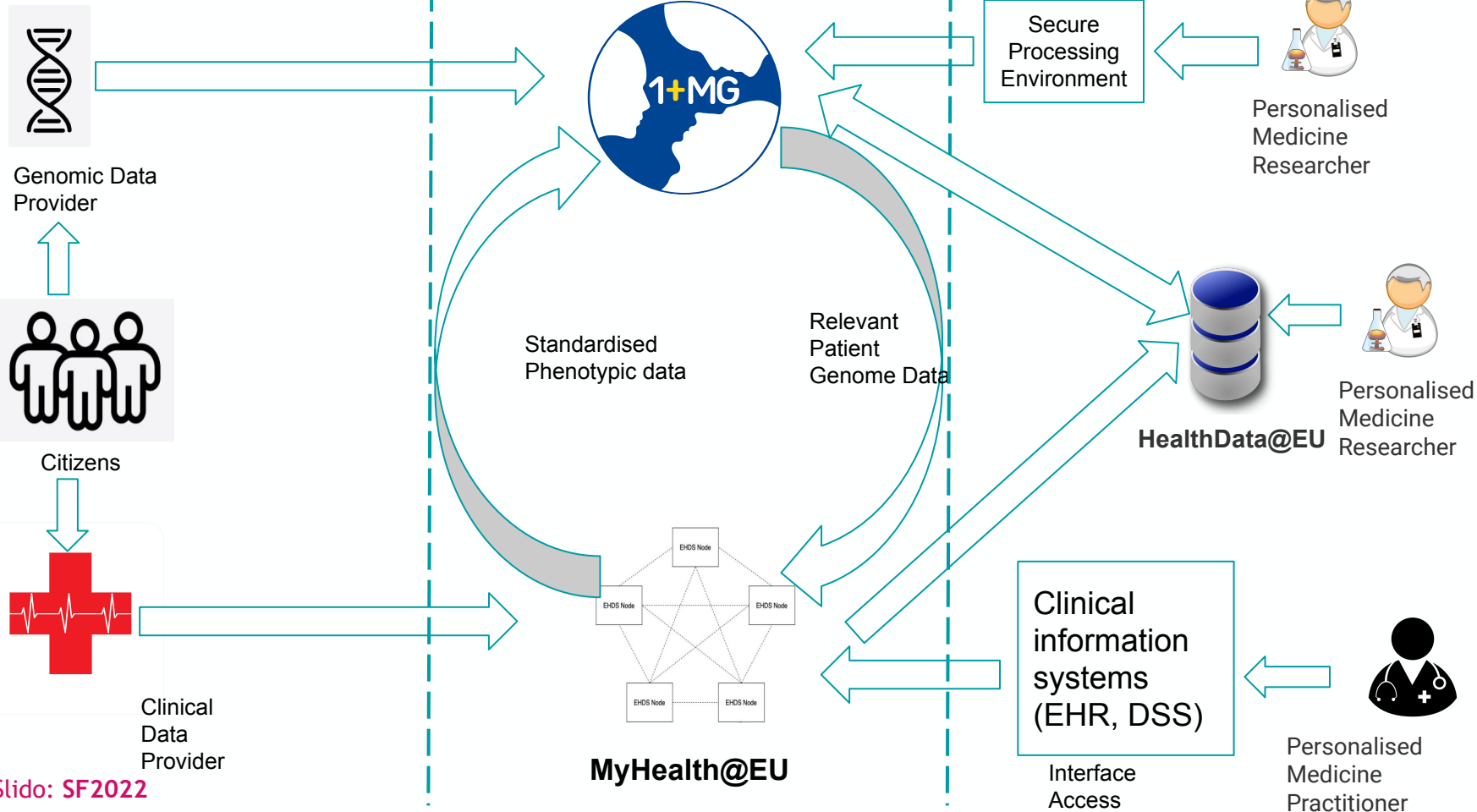
- Uses cases and users needs => clinicians, researchers, innovators
 - Genome of Europe
 - Cancer
 - Infectious Diseases
 - Common and complex diseases
 - Rare diseases
- Innovation solutions => for deployment on national nodes (Pillar II)
 - Federated analysis
 - Federated learning
 - Secured processing environments



Data Provision

Genomic Data infrastructure

Data Use



Opportunities for industry

- Deployment of the national nodes and national infrastructure
- Data discoverability
 - Obligation for healthcare and research data holders (public and private) in Europe to make data discoverable*
- Data access
 - Obligation for healthcare and research data holders (public and private) in Europe to make data accessible within two months of a data user request approved by EHDS Data Access Board*
- Capacity building
 - 1+MG Trust Framework experts
 - ✓ Data Governance(ELSI), Data Quality, Data Standards, Technical Infrastructure

Thank you!



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Audience Q&A Session

① Start presenting to display the audience questions on this slide.