Federated Data Governance and Analysis Platform for Cross-Institutional Health Research

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FACTS & FIGURES

Start date:	01.04.2023
End date:	31.03.2028
IHI funding:	23,032,209 €
Industry contribution:	19,671,182 €
Total Cost:	42,703,391 €
Project website:	https://www.iderha.org/
Social media:	https://linkedin.com/company/iderha

CHALLENGE

Research requires diverse, multi-source data, while regulations demand that sensitive data remain under institutional control. The "**code-to-data**" paradigm and **federated analysis** approach resolve this by keeping data private where they are held and returning only aggregated results that allow answering cross-institutional research questions.

The challenge is to provide a complete solution: a federated platform must give data providers reliable governance and data users sufficient flexibility, while satisfying security, technical and community standards, and legal and regulatory compliance.

APPROACH & METHODOLOGY

A collaborative platform design

Hospitals & registries
SAS · SERGAS · HULAFE · VTT

Legal & data protection
J&J · FHI · i~HD · Lygature - UNILU

Data science & AI use cases
FHI SCAI · TUM - MSB - Roche · VTT

Regulatory & HTA acceptance
NICE · DEFACTUM - …

Data standards & quality, interoperability
UNILU - i~HD · FHTW – ITTM – FHI ISST

Patients & citizens
MSB · ERS · Hygiaso

Requirements, constraints, limitations

ITERATIVE CO-DESIGN
UNILU · FHI ISST · Hygiaso

Data Holders WG · Data Access Task Force · AGM workshops
hackathons · weekly dev sync · bi-weekly project tech calls
SCRUM + Kanban · shared backlog · mutual review

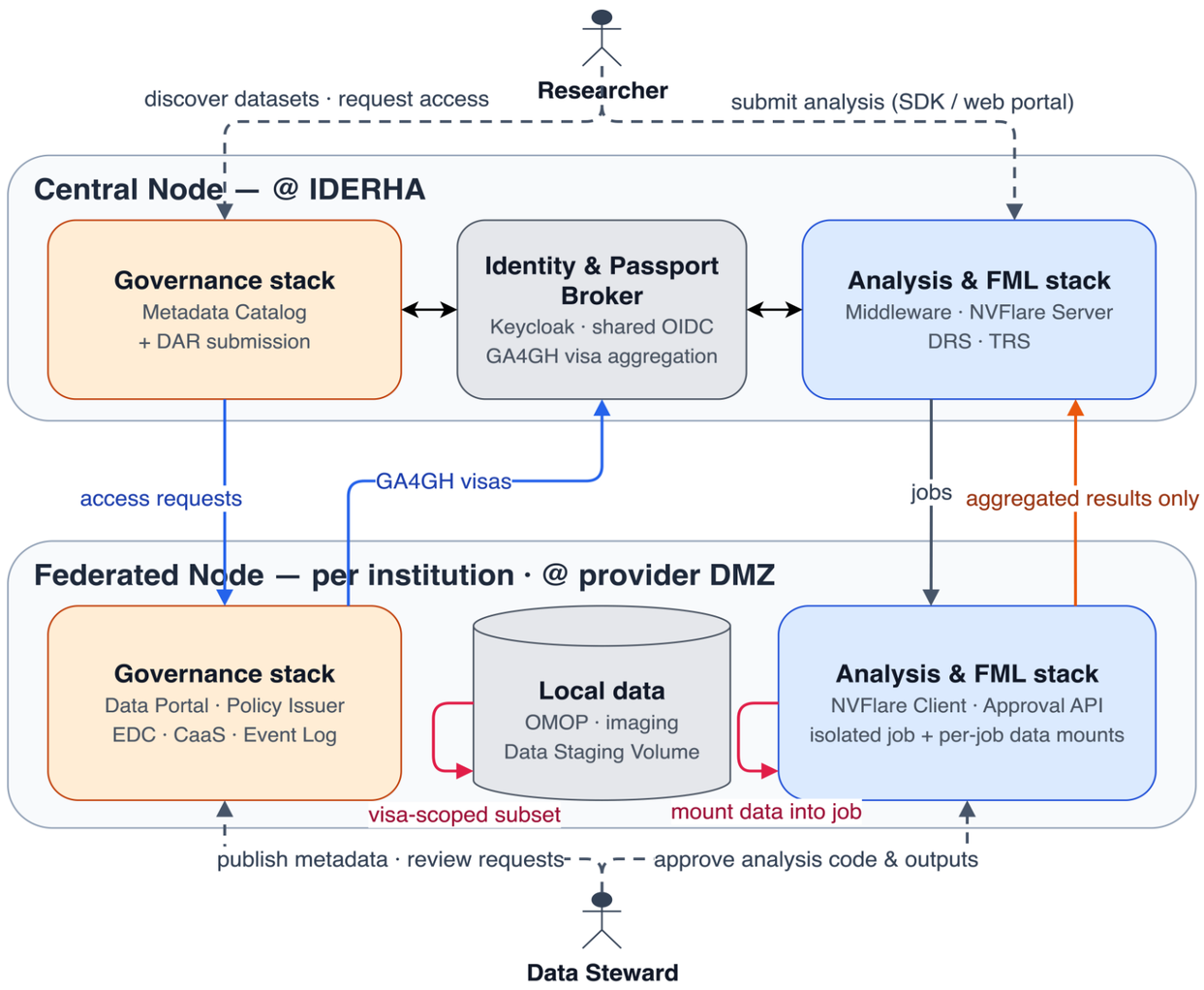
released, reviewed, revised

v0 (M12) design → **v1** (M18) *PoC* → **v2** (M24) *release* → **v3** (M36) *release* → **First real nodes** onboarding under way

RESULTS

A platform for federated data governance and analysis

- **Architecture:** designed, iteratively finetuned, implemented
- **Working software**: governance and analysis stacks on a three-node federation
- **From pilot to real sites**: lung-cancer federated learning pilot for FML approach validation; first node deployments



VALUE OF IHI COLLABORATION

- **Interdisciplinarity**: combining expertise and knowledge from multiple organisations across different domains: software engineering, data science, clinical, legal, regulatory and HTA expertise
- **Cross-border by design**: partner jurisdictions' legal and technical requirements contributing to one architecture
- **Access to real clinical sites:** several European hospitals and health services sharing data, validating and applying project's outputs within their infrastructures
- **Public–private reality check**: Perspectives, incentives and constraints from universities, hospitals, big pharma and SMEs contributing to feasibility and sustainability of the solutions
- **Plugged into the ecosystem:** Awareness and exchange with other initiatives and IHI/IMI projects to enable alignment and complementarity of the solutions

CAREER IMPACT

- **Gaining knowledge**: Gaining and integrating domain-specific knowledge from experts in multiple fields
- **Understanding landscape**: Learning needs, requirements, constraints, and approaches to health research from different perspectives (academia, big pharma, SMEs, regulators)
- **Managing project:** Gaining experience in managing international, interdisciplinary collaborations with complex requirements
- **Building visibility and connections**: Building professional and personal connections with project partners

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