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Prediction, monitoring and personalized recomendations for prevention and relief of dementia and frailty

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Realizing Ageing-EHDS: Advancing Data Integration and Secondary Use for Dementia Care within the COMFORTage Framework

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European Health Data Space - Vision

- **Empowers Citizens**: Enables individuals to have control over their health data, access it easily, and share it across borders in the EU.
- **Enhances Healthcare Delivery**: Supports healthcare providers with seamless access to relevant health data, improving diagnosis, treatment, and continuity of care.
- **Accelerates Research and Innovation**: Facilitates the use of aggregated and anonymized health data for scientific research, innovation, and policy development.
- **Strengthens Health Systems**: Provides tools for data-driven decision-making to enhance the efficiency and resilience of healthcare systems

European Health Data Space - Objectives

- Empower individuals to control their own data and facilitate the exchange of data across the EU.
- Provide a consistent, trustworthy, and efficient system for reusing health data for research, innovation, policy-making, and regulatory activities
- Foster a genuine single market for electronic health record systems

Primary use of data: ”EHDS1”

Secondary use of data: ”EHDS2”

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Impact of EHDS regulation on secondary use of health data

- **For Patients:**
  - Better access to their health data.
  - Seamless continuity of care across borders.
  - More personalized and effective treatments.
- **For Researchers and Innovators:**
  - Easier access to high-quality datasets.
  - Accelerated development of innovative healthcare solutions.
- **For Healthcare Providers:**
  - Faster access to accurate patient information.
  - Enhanced decision-making with comprehensive data.
- **For Governments and Policymakers:**
  - Improved insights into public health trends.
  - Data-driven policymaking and resource allocation.

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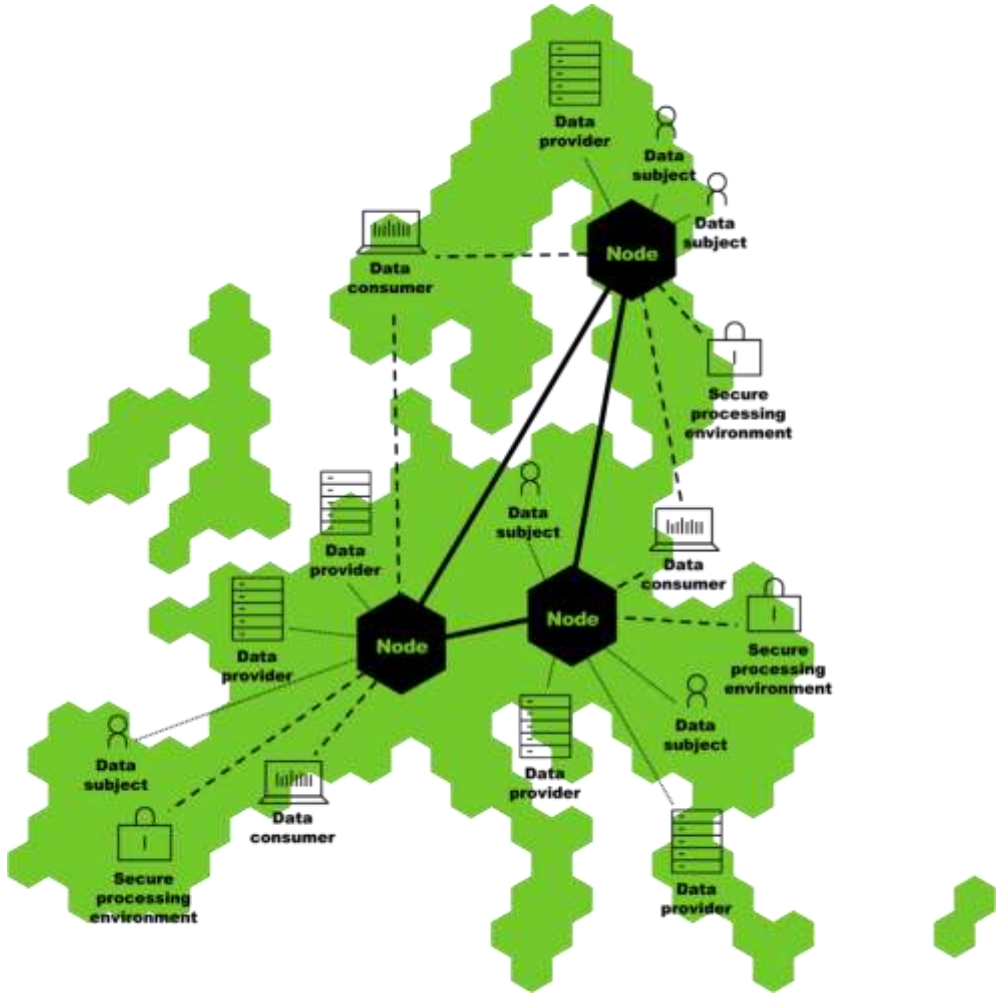
European Health Data Space - Framework

- **Governance Framework**
  - Health Data Access Bodies
  - EU Coordination
- **Interoperability Standards**
  - Electronic Health Records (EHRs)
  - Data sharing protocols , formats and ontologies
- **Data Sovereignty and Privacy**
  - alignment with GDPR and other privacy frameworks
- **Digital Infrastructure Development**
  - Cross-border data exchange systems
  - Platforms for secure access and aggregation of health data
  - AI and analytics tools for research and policy support



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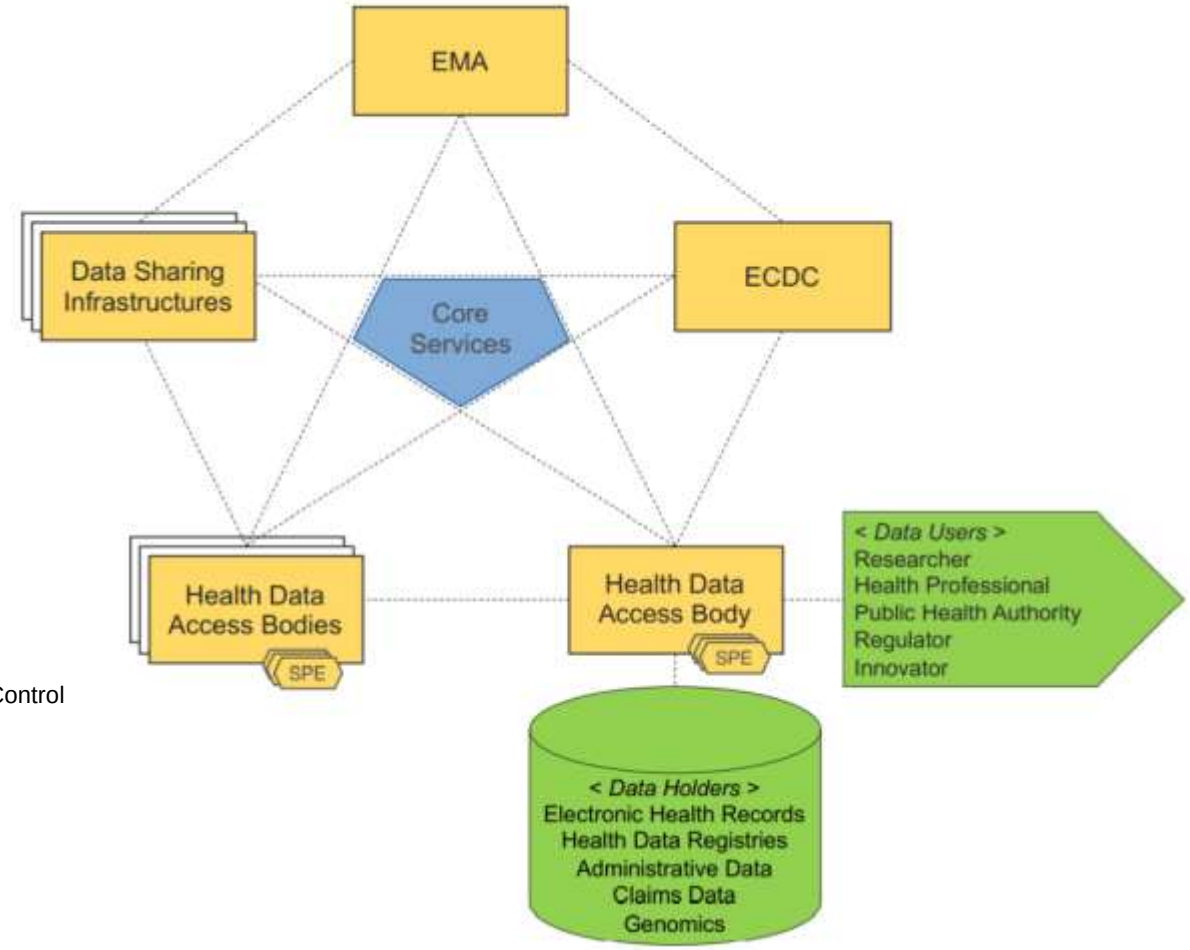
EHDS2 architecture



EMA: European Medicines Agency
ECDC: European Centre for Disease Prevention and Control
SPE: Secure processing environment

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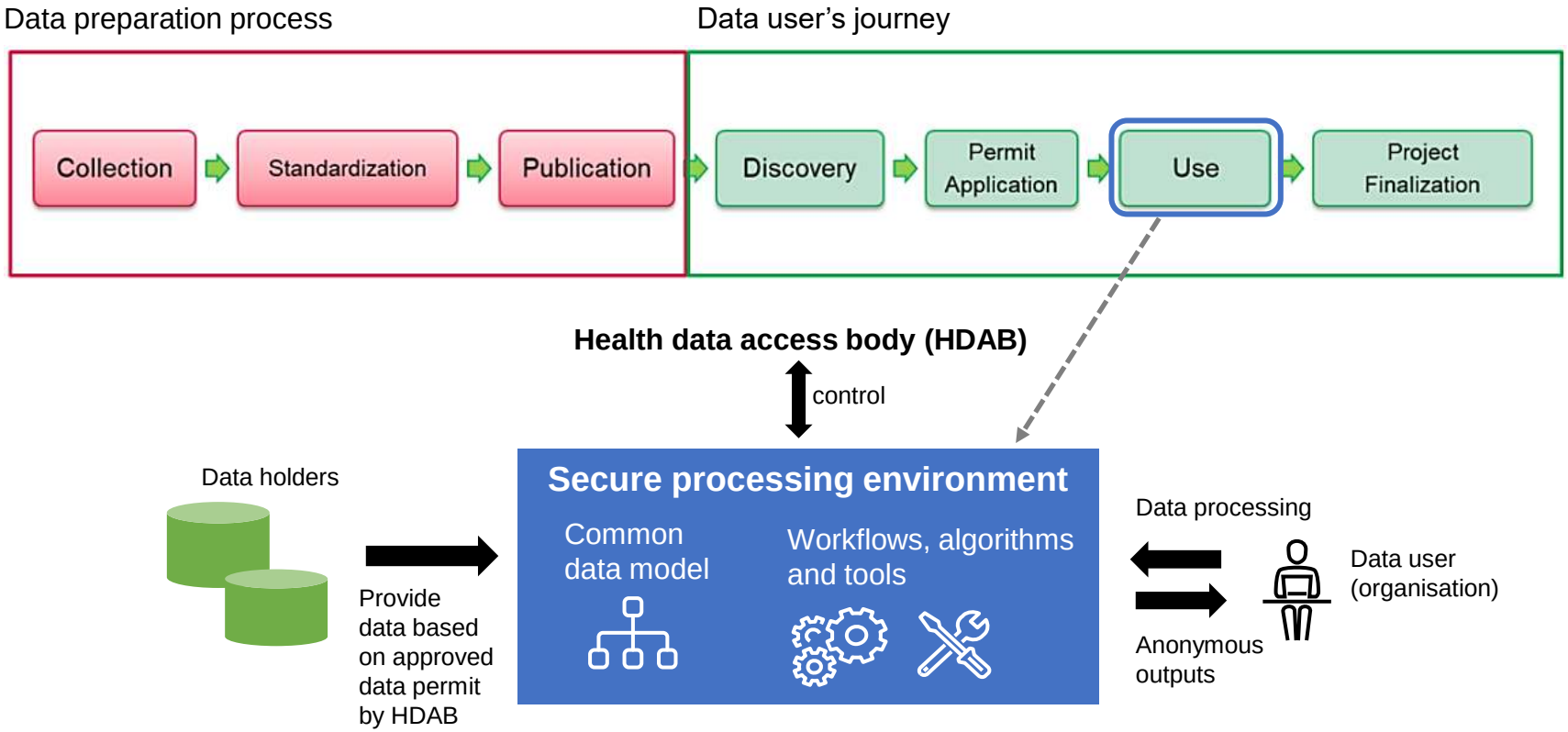
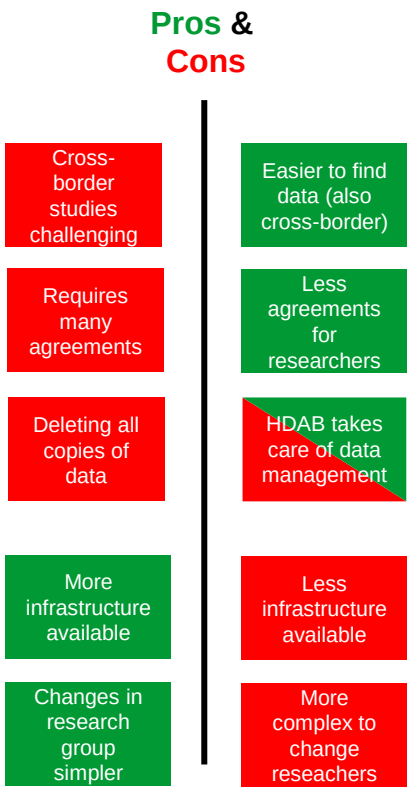
EHDS2 data access



Forced change how to work with data

- Traditional way:
  - Available data is found with data owner
  - Agreements signed about data usage, transfer and liability
  - Data collected from data owner systems and transferred to local machines or researcher's computer
  - Data is analyzed with available resources by research team or single researchers
  - After the project data is deleted according to agreements by data processor
  - Researcher is responsible for deletion



- EHDS way (proposed):
  - Data is searched from EHDS data catalog
  - Application is filled to EHDS system about selected data
  - HDAB processes the agreement and requests the data from related data owners and combines them
  - HDAB transfers the pseudonymized dataset to selected SPE and grants access to named researchers
  - Data is processed on SPE
  - Results and created codes are exported through HDAB
  - HDAB deletes the data and SPE environment when project ends

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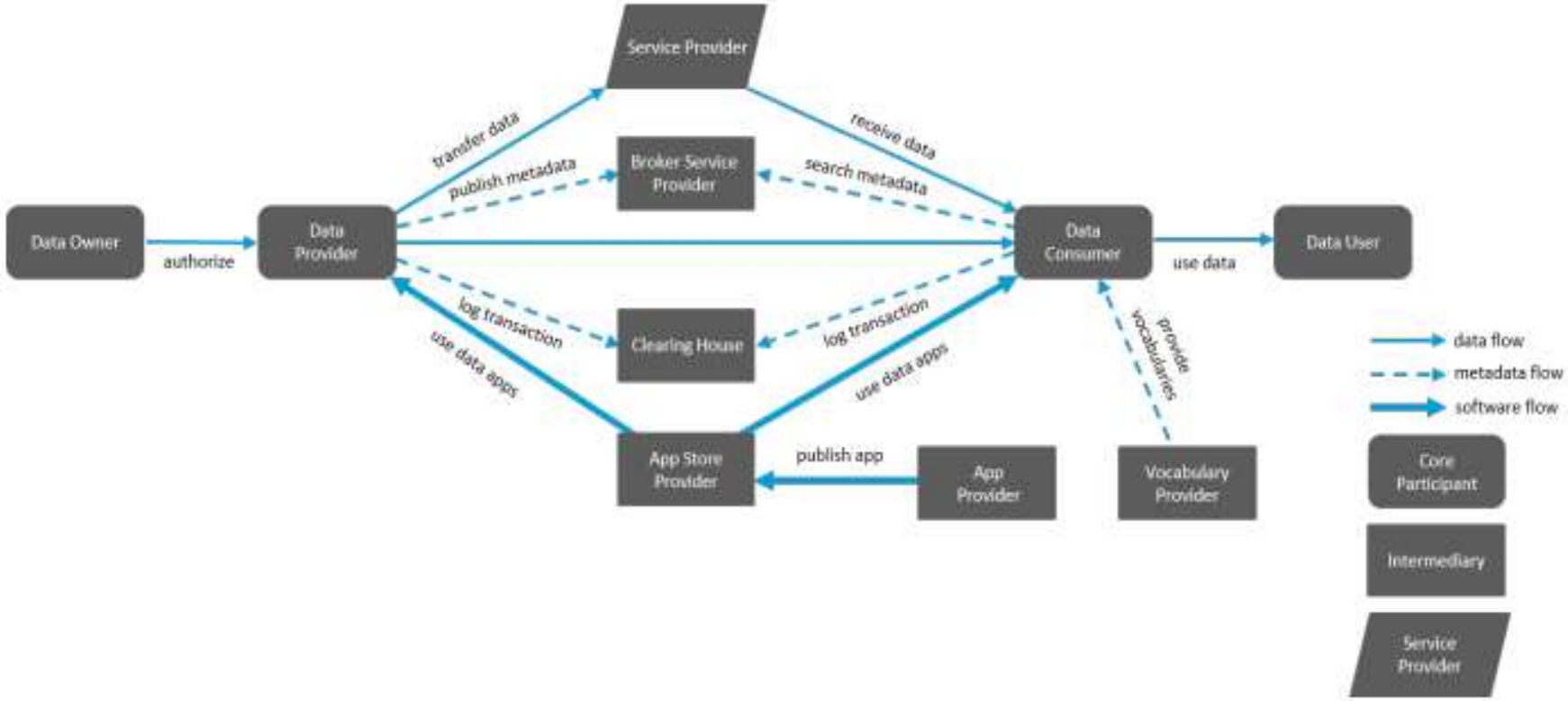
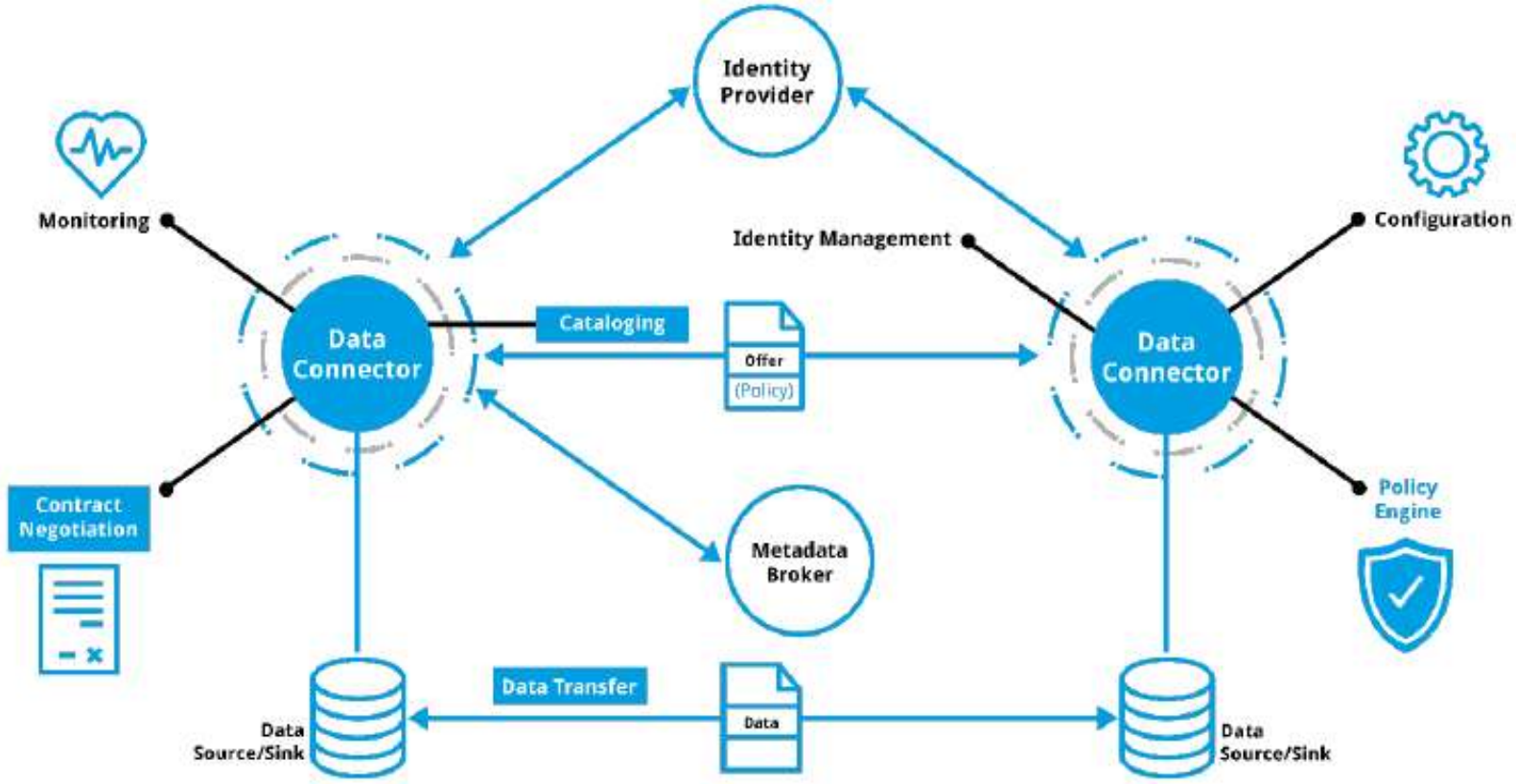
EHDS and the International Data Space Association

- **Shared Core Principles**
  - Data Sovereignty
  - Interoperability
  - Decentralization
  - Trust Frameworks



EHDS and the International Data Space Association

- **Technical Interoperability and Architectures**
  - IDS Connectors
  - Data Catalogs and Metadata Management



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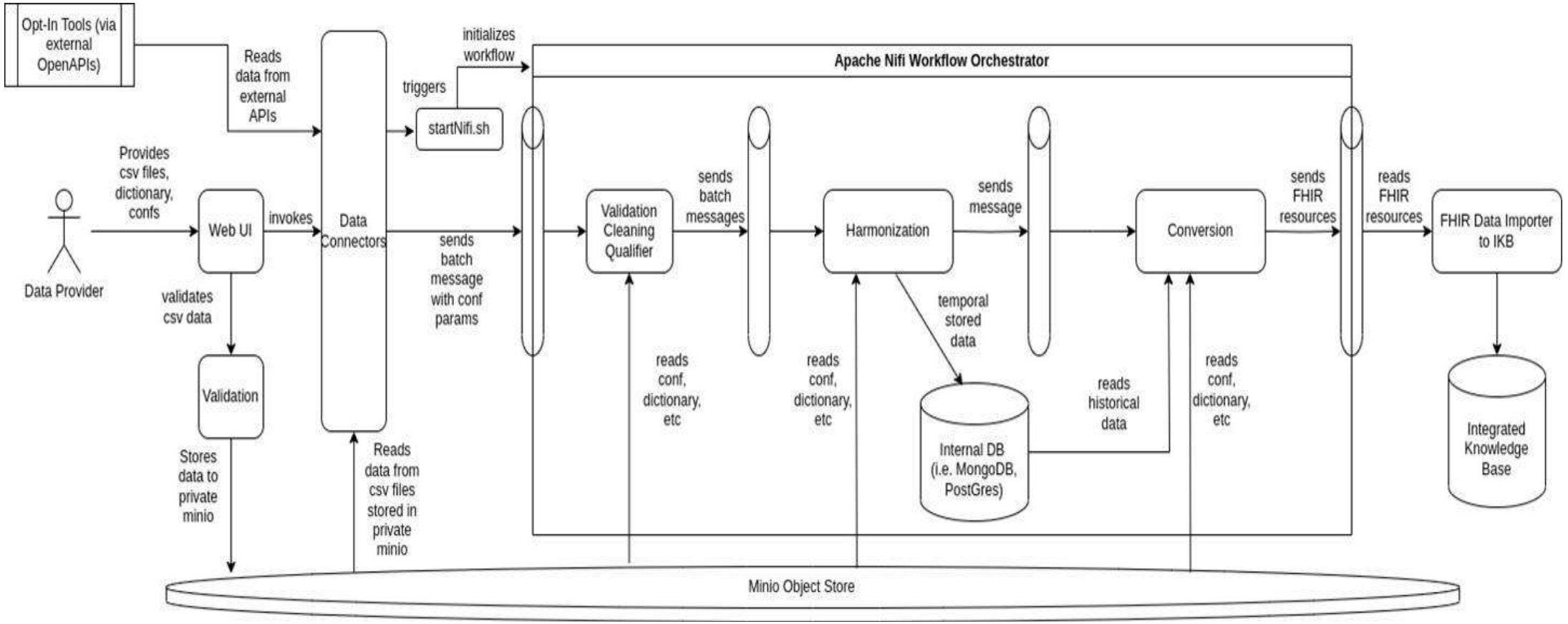
COMFORTage Data Ingestion Pipelines



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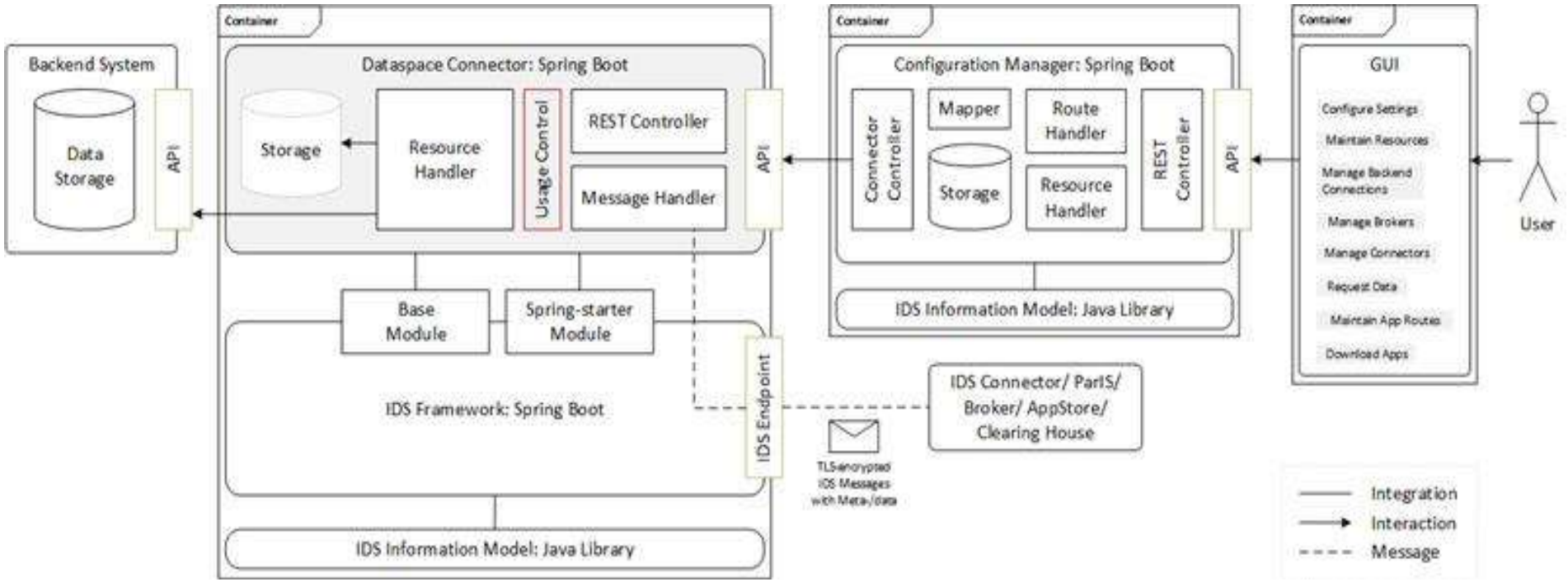
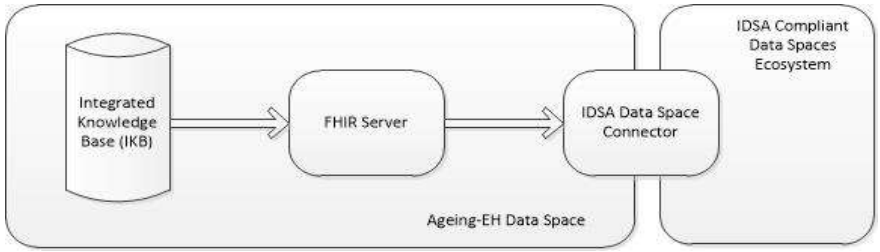
Ageing-EHDS compliance with IDSA





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Conclusions

- Ageing-EHDS shares the **same vision and principles** with the European Health Data Spaces
- Fosters **secondary use and sharing** of dementia related data
- Forces **interoperability standards**
- Preserves **data sovereignty** and **privacy**
- Achieves improved **integration** and **harmonization** of data collected from **diverse sources**
- Complies with the **Reference Architecture of the International Data Space Association** (IDSA)
- Integrates with the **IDS Data Connectors**

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