

NFDI4Health

A concept for a federated research data infrastructure for personal health data

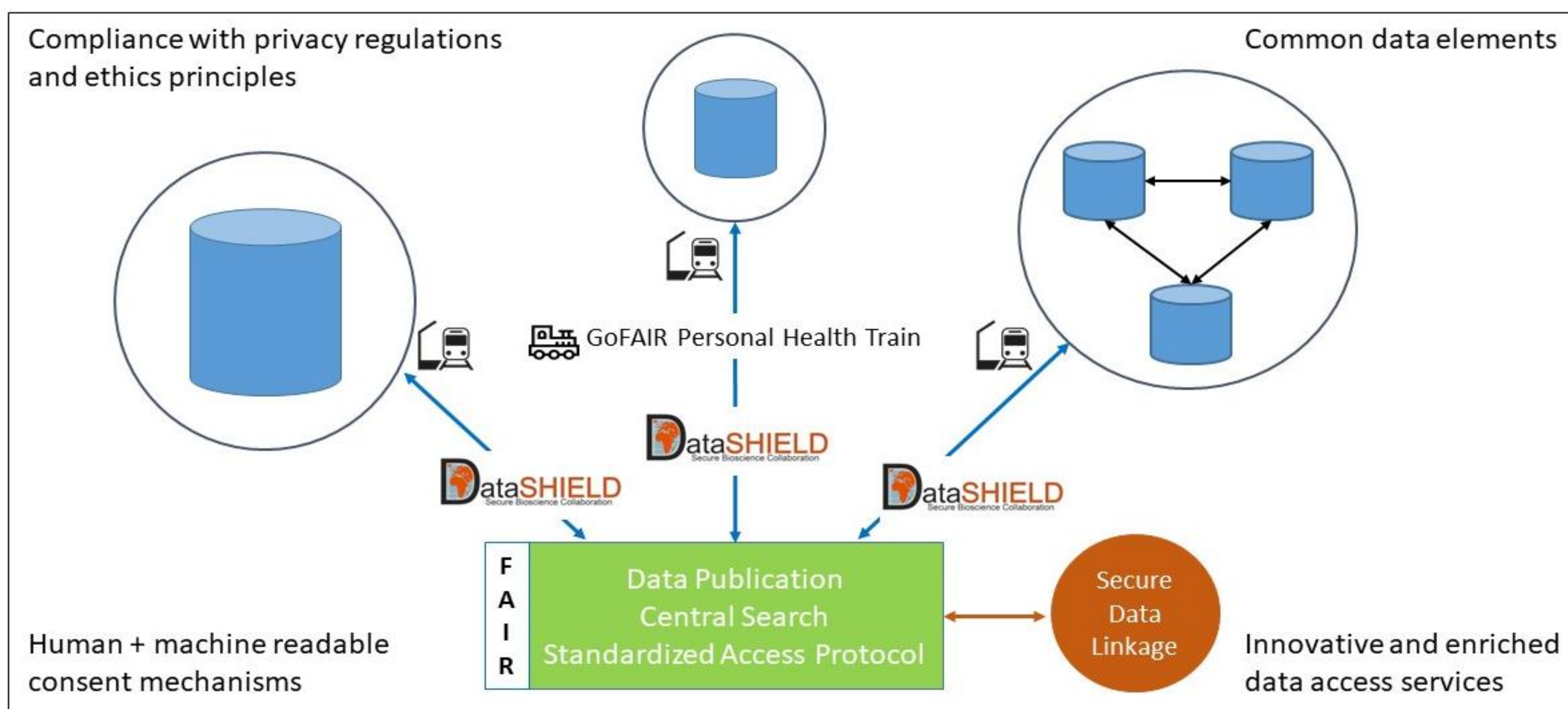
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Background NFDI: The national research data infrastructure (NFDI) is intended to systematically open up, sustainably secure and make accessible the databases of science and research and to network them (inter-)nationally. The DFG funds up to 30 domain specific consortia in order to build up the NFDI. The NFDI4Health consortium intends to submit a proposal to the DFG call closing on October 15th.

Current status of personal health data: Individual epidemiological studies and clinical trials are commonly highly standardised and well documented with structured, quality checked and curated data. **But:** they seldom fulfil **FAIR** principles: (1) **Findability** is often hampered. (2) Modalities of **data access** are typically not reported in sufficient detail. (3) Epidemiological databases are usually not **interoperable**. (4) Data protection requirements and boundaries set by the informed consent of study participants restrict **reuse** of data.

In NFDI4Health, major German providers of epidemiological/public health/cancer registry data, clinical trial registries as well as the clinical trial network coordination centre have joined forces with computer scientists, research data management specialists, and data mining experts to foster reuse of health-related data in the interest of improving population health.

NFDI4Health vision:



NFDI4Health objectives:

- (1) Enable findability of and access to structured health data
- (2) Establish a health data framework for centralised searching and accessing existing decentralised health data infrastructures
- (3) Facilitate data sharing, record linkage, harmonised data quality assessments, federated analyses in compliance with privacy regulations and ethics principles
- (4) Develop and deploy new, machine processable consent mechanisms and innovative data access services
- (5) Support cooperation between clinical research, epidemiological and public health communities
- (6) Foster interoperability of metadata repositories, cohort browsing, data quality and harmonisation
- (7) Develop business models to secure sustainability of structures and services

NFDI4Health implementation:

Task areas (TAs)

- Standards for Findability and Interoperability
- Services enabling (software development)
- Community and networking
- Use cases
- Privacy & data access in concert
- Enable future – Supporting AI



Use cases

- Use case: Exposure – Nutritional epidemiology
- Use case: Outcome – Chronic diseases
- Use case: Record linkage
- Use case: Clinical trials
- Use case: Surveillance
- Use case: ...

(Co-) applicant institutions:



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