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 fully 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:

Compliance with privacy regulations and ethics principles

Secure Data Linkage

Innovative and enriched data access services

Human + machine readable consent mechanisms

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:

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<thead>
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<th>Task areas (TAs)</th>
<th>Use cases</th>
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<tr>
<td>Standards for Findability and Interoperability</td>
<td>Use case: Exposure – Nutritional epidemiology</td>
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<tr>
<td>Services enabling (software development)</td>
<td>Use case: Outcome – Chronic diseases</td>
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<tr>
<td>Community and networking</td>
<td>Use case: Record linkage</td>
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<tr>
<td>Use cases</td>
<td>Use case: Clinical trials</td>
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<td>Privacy &amp; data access in concert</td>
<td>Use case: Surveillance</td>
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<td>Enable future – Supporting AI</td>
<td>Use case: …</td>
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