NFDI4Health

National Research Data Infrastructure for Personal Health Data

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NFDI Community Workshop, 25th June 2019, Bonn
### Community-Workshop

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<thead>
<tr>
<th>Zeit</th>
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<tr>
<td><strong>11:15 Uhr</strong></td>
<td>Einführung Marleen Grasse und Nina Winter, Landesinitiative NFDI der Digitalen Hochschule NRW</td>
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<tr>
<td><strong>12:00 Uhr</strong></td>
<td>Vorstellung der Initiative NFDI4Health, Juliane Fluck, ZB MED</td>
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<td><strong>12:45 Uhr</strong></td>
<td>Mittagspause</td>
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<td><strong>13:30 Uhr</strong></td>
<td>Einführung in die Arbeitsgruppen</td>
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<tr>
<td><strong>13:45 Uhr</strong></td>
<td>Arbeitsgruppen</td>
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<tr>
<td></td>
<td>- Erwartungen und Bedarfe aus Perspektive der DatennutzerInnen</td>
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<td>- Erwartungen und Bedarfe aus Perspektive der Datenlieferanten/lieferantinnen</td>
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<td>- Themenscout NFDI: welche Themen sind noch zu berücksichtigen?</td>
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<td>- Beteiligungsmöglichkeiten an NFDI4Health</td>
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<td><strong>15:15 Uhr</strong></td>
<td>Kaffeepause</td>
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<td><strong>15:30 Uhr</strong></td>
<td>Berichte und Zusammenfassung aus den Arbeitsgruppen</td>
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<tr>
<td><strong>16:00 Uhr</strong></td>
<td>Zusammenfassung und Ausblick</td>
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<td>Juliane Fluck, ZB MED</td>
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<td><strong>16:30 Uhr</strong></td>
<td>Ende</td>
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Who are we?

- Research institutes involved in the assembly as well in the analysis of personal health data from registries, cohort studies, clinical trials, administrative health databases, epidemiological and public health studies

- Infrastructure/standards and method development

- Addressing community
Personal Health Data

- Health data from registries, cohort studies, clinical trials, administrative health databases, epidemiological and public health trials

- Valuable Resources
  - Standardized and monitored data collection based on trial protocols,
  - Deep and purpose-specific phenotyping,
  - Repeated examinations with standard examinations and
  - Structured and annotated data items
Personal Health Data

- Health data from registries, cohort studies, clinical trials, administrative health databases, epidemiological and public health data

- Special characteristics
  - Very sensitive data and creation of absolute anonymity not possible (→ data protection important)
  - Living data sets with need for continuous maintenance and update
  - Data usage based on informed consent of participants
  - Data linkage of special interest and with particular challenges
Personal Health Data

- Health data from registries, cohort studies, clinical trials, administrative health databases, epidemiological and public health data

- Current restrictions
  - Across different databases and studies, standardization or interoperability are often lacking
  - Metadata descriptions missing
  - Findability of the resources hampered
  - The opportunities for access are currently very restricted
  - No data mining and machine learning approaches possible
Challenges

- Cultural change to share data
- Common efforts to create meta data repository
- Framework for protected data sharing
- Sharing across disciplines

- Many closed isolated sources
- Limited access
- Interoperability is limited
- Findability is hampered
- No data linkage
Vision

Adress data producer as well as consumer/analysts

Compliance with privacy regulations and ethics principles

Common data elements

Human+Machine readable consent mechanisms

Data Publication
Central Search
Standardized Access Protocol

Secure Data Linkage

Innovative and enriched data access services

DataSHIELD

GoFAIR Personal Health Train

Secure SHIELD

German Institute of Human Nutrition Potsdam-Rehbrueck

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Stakeholders

- Participating networks, associations and umbrella organisations bring in existing user communities

- Professional societies guarantee broad access:
  - German Public Health Association (DGPH)
  - German Society for Epidemiology (DGEpi)
  - German Association for Medical Informatics, Biometry and Epidemiology (GMDS)
  - German Society of Social Medicine and Prevention (DGSMP)
  - ...
A health data framework for centralized searching and accessing existing decentralized, autonomous epidemiological and clinical data infrastructures

Enhanced interoperability, data sharing and data linkage of personal health data in compliance with privacy regulations and ethics principles

Metadata library/repository and supporting tools for annotation of data

Machine readable consent mechanisms and innovative and enriched data access

Summary NFDI4Health

Enabling full exploitation of existing health databases
Questionnaire for Community

Please give us feed back by answering our online questionnaire

Thank you very much for your attention!