NFDI4Health

National Research Data Infrastructure for Personal Health Data

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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

Centre for clinical trials Leipzig

Associated:
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- Infrastructure/standards and method development.

Associated:

- Centre for clinical trials Leipzig

- KKS Netzwerk
- DE.NBI
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- 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 studies

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

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

- 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

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- 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
NFDI4Health - Strategy

- Set up of metadata library/repository in order to harmonize and standardize metadata for clinical and epidemiological studies and further data sets in the health care system
- Development/advancement of data analysis services that allow controlled access to distributed databases and guarantee the use of the data exclusively in accordance with the declaration of consent.
- Development of services for dynamic and secure linkage of primary, secondary and register data
- Archiving of study data and metadata for access (data sharing) and reproducibility of results
What do we offer to NFDI

- 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
Future plans

- Recommendation to **merge consortia in field of medicine**
  - Meeting on June 13th, 2019
  - Presumably one big consortium

- **NFDI4Health meeting** on June 24th, 2019
  - Based on decision (see above)
    - Governance
    - Work package structure
    - Financial plan
    - Responsibilities

- **Community workshop** on June 25th, 2019
Thank you very much for you attention!

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