Welcome to the FDPG workshop

Juliane Fluck
NFDI4Health Spokesperson
Why does NFDI4Health organise this workshop

➤ We are closely collaborating with MII since

  o we have a high number of partners participating in MII and NFDI4Health
  o we would like to uptake everything already on the way in the MII:
      o Standards already consented within the MII (terminology and interfaces)
      o Software explicitly the software FDPG

  Advantage that we could participate in the requirement analysis
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Mission of NFDI4Health

Our mission:

▪ to increase the value of research in epidemiology, public health, and clinical trial based medicine

▪ by making high quality data internationally accessible according to FAIR principles

Vision:

to boost scientific exploitation of personal health data
Data body in NFDI4Health

Primary focus

- Epidemiological and public health studies
- 26 local studies with > 400,000 participants
  - German National Cohort
- Clinical studies
  - 24 university study centres

Secondary focus

- Health registries
- Administrative health databases
Amalgamation of epidemiology, public health and clinical research

- Common search and data access services
- Common standards for (meta-)data
- Common data structures
- Common consent forms

Open up the silos and boost the scientific exploitation of personal health data
German Landscape Health Research Data Infrastructures

NFDI

Health Study Data  Human Omics Data

Health Insurance Data  Health Registry Data  Health Care Data

Differences: Content  |  Responsibilities  | Legal Regulations

Health Data Lab  > 300  33 Data integration centres

Federal Institute for Drugs and Medical Devices  German Centre for cancer registry

+ many research related infrastructures, e.g. University Medicine Network (NUM), German Centers for Health Research (DZGs), Helmholtz Health.
European Health Data Space

- Better diagnosis and treatment, improved patient safety, continuity of care and improved healthcare efficiency
- Empower **individuals** to have control over their health data
- Enable **health professionals** to have access to relevant health data
- Assist **policy makers and regulators** in accessing relevant non-identifiable health data
- Facilitate access to non-identifiable health data for **researchers and innovators**

Mission II

Establish NFDI4Health as one of the relevant health data infrastructures in the German and European Health Data Space
Data publication as a solution to make study data findable

NFDI4Health partners and task areas are

➢ working on commonly accepted metadata scheme for publication of study data (findability, not public availability)
➢ developing a Central Health Study Hub for study data publishing, search and cohort browsing
➢ working on common interfaces e.g. for metadata extraction

➢ performing community work for the establishment of data publications
➢ supporting data publication through data stewards (newly installed).
NFDI4Health – Solutions: 1. Central Findability of Studies

- Meta-Data
- Protocols
- Data dictionaries
- Data collection instruments
- ...

German Central Health Study Hub

Studies

MDR* Document repository

Data collection instruments

*Meta-Data-Repository

Data holding organisation

Make study data publishing a normal and accepted process!

Get reputation for study data publications!

https://covid19.studyhub.nfdi4health.de/
Data Access

To be started

- Central process for requesting data use and access
- Transparent overview of applications
- Decision-making process remains with the local data holders

- No common data packages / consent / data use and access for the NFDI4Health data holders

German Central Health Study Hub
NFDI4Health Research Data Portal (based on FDPG)

No centralised access or transfer of personal health information

Local Request Management

Forschern:innen
Questions to be addressed today

➢ How far is FDPG ready to serve as a central portal for application processes forwarded to the data holding organisations

➢ How far is FDPG ready to serve as portal for other health infrastructures/data holding organisations?

➢ Is FDPG a good base to develop the software further toward the requirements identified above?

➢ Independent from FDPG - what is the minimum level we have to agree on to reach interoperability for the application process?

➢ Does it make sense to join forces for the further development of FDPG?
NFDI4Health consortium

- Research institutes involved in data collection and analysis of personal health data
- Infrastructures / experts in development of standards and methods
- Institutions with focus on involvement of the user community
- 47 renowned institutions as participants
Questions?

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ZB MED – Information centre for Life Sciences
www.nfdi4health.de

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Projects with the German Centers for Health Research (DZGs)

Seed funding via flexfunds in 2022 to start DZG cooperations

1. The Working Group Data Management of the DZGs
2. Newly founded **German Center for Child and Adolescent Health (DZKJ)**

- (Meta)Data publications
  - (Meta)Data Scheme + concepts for specific collections
  - Interfaces
  - Standards
  - Content Exchange
Enabling automatic analysis in distributed analysis platform

- Central Client-Server for DataSHIELD and Personal Health Train (PHT).
- Application-related integration of partners.
- Partner select and share data locally.
- Data harmonisation necessary.