NFDI4Health – National Research Data Infrastructure for Personal Health Data: The Role of Libraries

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Abstract

In Germany, the federal and state governments have been funding the development of a National Research Data Infrastructure (NFDI) since 2020. The NFDI is intended to set standards in data management and to sustainably secure research data and make it re – usable. Besides, the NFDI will ensure connectivity, to international developments like the European Open Science Cloud.

Funding is provided within the framework of up to 30 consortia, which take care of the data by a discipline specific community. Since October 2020, the first 9 consortia have started their work. Among them are two consortia with a medical focus: German Human Genome Phenome Archive and National Research Data Infrastructure for Personal Health Data (NFDI4Health).

NFDI4Health focuses on individual epidemiological and clinical studies and public health surveys. These are generally highly standardized and well documented with structured, quality-controlled, and curated data. However: (1) ability to find data is often impeded. (2) Data access modalities are generally not described in a sufficient detail. (3) Epidemiologic databases are generally not interoperable. (4) Privacy requirements and limits imposed by informed consent of study participants restrict data re-use.

Goals of NFDI4Health in this context are:

(1) Enable ability to discover and access structured health data,

(2) Maintain a federal framework for data-holding organizations,

(3) Enable exchange and linkage of personal data while maintaining privacy,

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(4) Establish automated services (e.g., utilization and access, analytic tools),

(5) Establish interoperability and reusability of data,

(6) Promote use-case oriented collaboration among research communities.

Scientific libraries are involved in the consortium as leading partners and cooperate in the project with 17 other partners. The Information Centre for Life Sciences (ZB MED) has taken over the project coordination and is also responsible for the work packages: "Standardisation" and „Services", which include the ways of simplifying data publication, elaborating publication guidelines, and developing a central search portal. Furthermore, the University Library at the University of Cologne (USB) is responsible for the work package "Community Integration". As part of this work package, an idea was developed on how university or medical libraries can be integrated as multipliers for consultation as well as for education and training offers on the management of research data from epidemiological and clinical studies. Both ZB MED and USB will serve as hubs to connect local researchers and infrastructure providers with NFDI4Health.

The presentation will introduce both the concept of NFDI and NFDI4Health and the role of libraries in the project demonstrating how libraries can be part of a dynamic research data management infrastructure at a national level.

Keywords: Health Data, Research Data Management, Epidemiological Study, Clinical Study

Bibliography

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