### Overview

[NFDI4Health](https://www.nfdi4health.de/en/) stands for "National Research Data Infrastructure for Personal Health Data in Germany". It is part of a network of 30 [NFDI consortia](https://www.nfdi.de/consortia/?lang=en) covering different scientific disciplines like chemistry or cultural heritage. All NFDIs got a five-year grant (2020-2025) from the German Federal Ministry of Education and Research (BMBF). The main goal is **to build a networked infrastructure and connect existing datasets**.

NFDI4Health provides a broad coverage of biomedical data-driven projects like:

* epidemiological cohorts
* clinical trials
* public health surveys
* administrative databases

NFDI4Health is strongly committed to the ideas of FAIR data management.

However, as personal and particularly sensitive data, health data are subject to special protection regulations. They may only be made available to third parties with the patient's consent or after de-identification. Furthermore, accompanying study materials such as protocols, descriptions of data catalogs or data entry forms are in part considered intellectual property and are only published in an incomplete manner.

In the context of the Sars-Cov-2 pandemic, as in many consortia, a special intitiative was created to support research. The [NFDI4Health Task Force COVID-19](https://www.nfdi4health.de/en/task-force-covid-19/) is developing, among other things, a hub of clinical and epidemiological studies in Germany related to Covid-19: the [**COVID-19 Study Portal**](https://covid19.studyhub.nfdi4health.de/).

### Technical background

The study portal consists of three main parts:

1. The [central serach hub](https://covid19.studyhub.nfdi4health.de/) serving as a study registry. The search hub is an in-house development.
2. The [asset repository](https://csh.nfdi4health.de/) for maintaing all study-related digital resources like documents or datasets. The asset repository is based on the [FAIRDOM-SEEK](https://fair-dom.org/instance.html) research data management system.
3. The [study catalogue browser](https://studycataloguebrowser.ship-med.uni-greifswald.de/) giving insight to the case report forms, instruments or assessments used. It is based on [Opal](https://www.obiba.org/pages/products/opal/) and [Mica](https://www.obiba.org/pages/products/mica/).

### Example application

Typical research studies such as [SHIP-COVID](https://covid19.studyhub.nfdi4health.de/resource/20181) have a complex structure and can be characterized by a variety of attributes. One problem here is the low consensus on the meaning and value list options of individual attributes. Especially generic attributes such as study type, study focus, primary objective, or target population are understood differently in clinical trials than in epidemiological cohorts. Individual parameters such as phase, arm, or investigational drug are specific to individual research areas.

A [custom metadata schema](https://pubmed.ncbi.nlm.nih.gov/34042687/) with approximately 100 attributes was designed for the Covid-19 study portal. There are still ambiguities in the practical use by external users.

### Options for utilizing FHIR4FAIR

The NFDI4Health Taskforce has been working on the possibility of using the HL7-FHIR standard while respecting the concepts of FAIR from the very beginning. Unfortunately, the spread of FHIR in clinical research is currently (as of 2020/2021) still manageable. Currently, a mapping of the metadata schema to FHIR is being developed and evaluated. It can already be foreseen that the inherent support of [metadata](https://confluence.hl7.org/display/SOA/Metadata+and+data), [identifiers](https://confluence.hl7.org/display/SOA/FHIR+identifiers+and+FAIR+principles+on+IDs) and [terminologies](https://build.fhir.org/ig/HL7/fhir-for-fair/terminology.html) will be of great help. Later applications will eventually be natively based on FHIR.

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