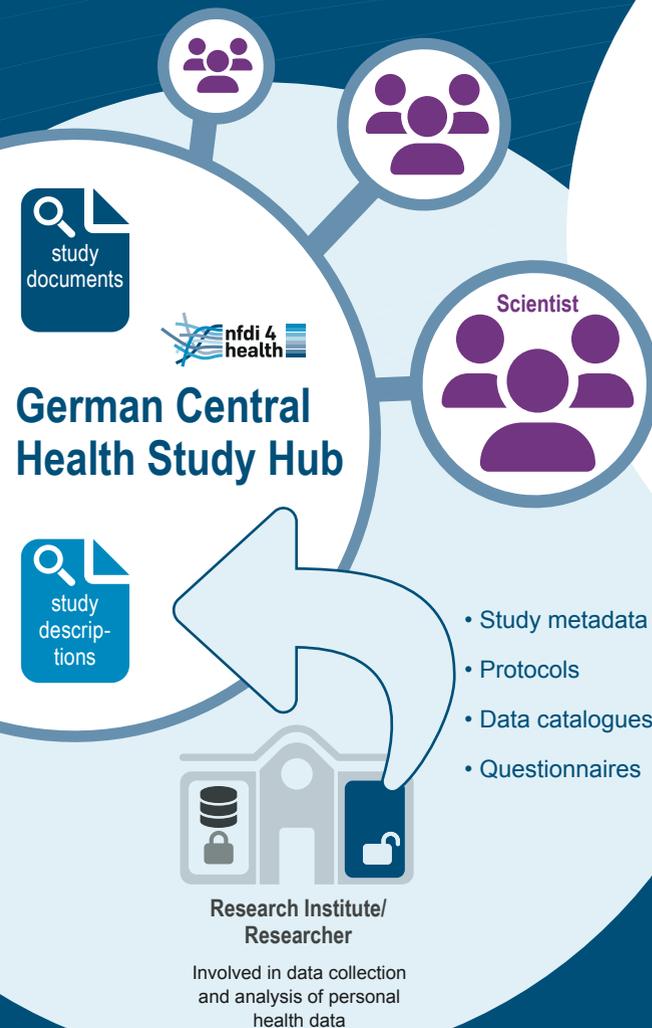


Why should I share data with NFDI4Health?

By publishing your study description with meta-data, a persistent identifier and license information, you adhere to some FAIR criteria. It also enhances reputation and cooperation.



What is NFDI4Health?

The National Research Data Infrastructure for Personal Health Data is a DFG-funded project and has been running since October, 2020 (project number 442326535). Our main goal is to support the clinical and epidemiological research community in sharing their data with the user community in accordance with privacy regulations and ethical principles, and to create new data analysis opportunities in the interest of improving population health.

How can you contact us?

General inquiries:
contact@nfdi4health.de

If you need help sharing or preparing data,
we are here to help:
studyregistration@nfdi4health.de

Contact



Study registration



Website



How can I share data with NFDI4Health and why?



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What kind of data?

Study descriptions that contain comprehensive information (metadata) about interventional or non-interventional studies from the clinical, epidemiological, or public health fields.

Study documents that contain information about studies or research-related content such as design, conduct or instruments. For this resource, the data files themselves or only the meta data describing the file can be shared.

Please note that individual participant/patient data collected as part of studies will not be included.

Considerations

Licenses

Descriptive data (metadata) that characterize a study are license-free. Likewise, descriptions such as titles, authors and abstracts of documents are not subject to licensing. In contrast, a document is a copyrighted work. Therefore, a license is required before it can be shared, and the choice of license is the responsibility of the author. Licenses can range from “no use without explicit permission” to “free reuse including adaptation”. Less permissive variants are preferred.

Data formats

Data can be available in a variety of formats. In principle, sharing in any format is reasonable and possible with NFDI4Health. However, file formats should ideally be open and machine-readable such as .csv, .json, or .txt.

How can I share data with NFDI4Health?

1. Define your data type

- Submit metadata descriptions including license and access information to the [German Central Search Hub](#). It is important to note that no individual participant/patient data will be shared through the platform.
- Publish study documents such as data dictionaries, study protocols, questionnaires, codebooks, or survey questionnaires (CRFs).

2. Define your data format

- The metadata of a study can be entered via a web form or submitted via an API. The latter makes sense if you are a research data center and regularly perform studies.
- For document publication, there is no specific document format required, all formats are accepted. However, open (non-proprietary), machine-readable, and –processable formats such as .xml, .csv, .json, .txt, PDF(A), or .rdf are preferred.

3. Choose your license

Different licenses are possible for a study document. Creative Commons licenses are desirable, but licenses that restrict the reuse of your data more are also possible. The exclusive rights remain with the authors. Further information can be found in our flyer “Publish study documents and survey instruments quickly and easily”.

4. Submit your data

There are two ways to submit your data.

- (i) You complete the web form on our [German Central Search Hub](#).
- (ii) You use an API to automatically submit metadata and documents to the portal.

5. Assign a DOI

For your documents, we can assign you a DOI, a Digital Object Identifier. With this persistent identifier, your document is uniquely referenceable worldwide and thus not only permanently findable, but also citable.

6. Your data is displayed

The [German Central Health Study Hub](#), NFDI4Health’s portal to which your data is submitted, increases the visibility of your studies and documents and makes them accessible to a wide audience. This also allows researchers to gain reputation.

