

FAIR-Evaluation an den NUM-Standorten - Wie FAIR ist NUM?

Vielen Dank für Ihre Bereitschaft zur Teilnahme an der Umfrage "FAIR-Evaluation an den NUM-Standorten - Wie FAIR ist NUM?". Diese Umfrage wird durch CODEX+ WP2.2 durchgeführt und ausgewertet.

2016 wurden die "FAIR Guiding Principles for scientific data management and stewardship" veröffentlicht. Sie beschreiben verschiedene Anforderungen an Forschungsdaten bzgl. deren Auffindbarkeit, Zugänglichkeit, Interoperabilität und Wiederverwendbarkeit. Neben allgemeinen Empfehlungen beinhalten die FAIR-Prinzipien ebenfalls eine Reihe konkreter Maße für die sog. "FAIRness" von Forschungsdaten.
Mehr unter: <https://www.go-fair.org/fair-principles/>

Die Umfrage nimmt insgesamt etwa ca. 15-20 Minuten in Anspruch. Ihnen werden hierbei sowohl allgemeine Fragen zu Ihrem Projekt, als auch spezielle Fragen die vier FAIR-Kategorien (Findability, Accessibility, Interoperability, Reusability) betreffend gestellt. Die Freitext-Antworten können auf deutsch sowie englisch angegeben werden.

Ziel unserer Umfrage ist es in Erfahrung zu bringen, in wie weit die FAIR-Prinzipien in den verschiedenen Projekten bereits Anwendung finden, um somit im weiteren Schritt unserer Arbeit zu erkennen auf welche Weise man die FAIRness der Projekte verbessern kann.

Im Folgenden ist mit dem Begriff "data" die in Ihrem Projekt bearbeiteten/vorhandenen Daten im Allgemeinen gemeint. (z.B. Software oder Dokumentation)
Im Folgenden ist mit dem Begriff 'dataset' zu verstehen: Ein Datensatz ist eine Sammlung zusammenhängender, diskreter Daten, auf die einzeln oder in Kombination zugegriffen werden kann oder die als Ganzes verwaltet werden. Wir möchten Sie darauf hinweisen, dass die Teilnahme an dieser Umfrage freiwillig ist und Sie die Befragung jederzeit beenden können. Aus einer möglichen vorzeitigen Beendigung der Befragung entstehen Ihnen keinerlei Nachteile.

Die hier erhobenen Daten werden vertraulich behandelt und nur in anonymisierter und aggregierter Form für die weitere Arbeit innerhalb von NUM verwendet und können für wissenschaftliche Analyse in Publikationen genutzt werden. Es werden keine personenbezogenen Daten erhoben, verarbeitet oder gespeichert. Wir planen die Ergebnisse Ende 2022 vorzustellen.

Sollten Sie Fragen zu dieser Umfrage haben, können Sie sich an Lea Michaelis, E-Mail: lea.michaelis@med.uni-greifswald.de wenden.

Vielen Dank!

Lea Michaelis, Michael Muzoora, Rasim Atakan Poyraz, Dagmar Waltemath

Kontakt: lea.michaelis@med.uni-greifswald.de

----- EN Version -----

Thank you for your willingness to participate in the survey "FAIR evaluation at NUM sites - How FAIR is NUM?". This survey will be conducted and evaluated by CODEX+ WP2.2.

In 2016, the "FAIR Guiding Principles for scientific data management and stewardship" were published. They describe various requirements for research data regarding their discoverability, accessibility, interoperability and reusability. In addition to general recommendations, the FAIR principles also include a number of concrete measures for the so-called "FAIRness" of research data.
More at: <https://www.go-fair.org/fair-principles/>

The survey will take about 15-20 minutes to complete. You will be asked general questions about your project as well as specific questions about the four FAIR categories (Findability, Accessibility, Interoperability, Reusability). The free text answers can be given in German as well as in English.

The aim of our survey is to find out to what extent the FAIR principles are already applied in the different projects, in order to identify in a further step of our work how the FAIRness of the projects can be improved.

In the following, the term "data" refers to the data processed/existing in your project in general. (e.g. software or documentation)

In the following, the term 'dataset' means: A dataset is a collection of related, discrete data that can be accessed individually, or in combination, or that is managed as a whole.

Please be advised that participation in this survey is voluntary and you may terminate the survey at any time. You will not suffer any disadvantages from a possible premature termination of the survey.

The data collected here will be treated confidentially and will only be used in anonymized and aggregated form for further work within NUM and may be used for scientific analysis in publications. No personal data will be collected, processed or stored. We plan to present the results at the end of 2022.

If you have any questions about this survey, please feel free to contact Lea Michaelis, email: lea.michaelis@med.uni-greifswald.de.

Thank you.

Lea Michaelis, Michael Muzoora, Rasim Atakan Poyraz, Dagmar Waltemath

Kontakt: lea.michaelis@med.uni-greifswald.de

For what NUM-site are you answering?

- ☐ Deutsches Krebsforschungszentrum (DKFZ)
- ☐ Fraunhofer Gesellschaft
- ☐ HiGHmed e. V.
- ☐ TMF e.V.
- ☐ Universitätsklinikum Aachen
- ☐ Universitätsklinikum Augsburg
- ☐ Charité - Universitätsmedizin Berlin
- ☐ Universitätsklinikum der Ruhr-Universität Bochum
- ☐ Universitätsklinikum Bonn
- ☐ Technische Universität Darmstadt
- ☐ Universitätsklinikum Carl Gustav Carus Dresden
- ☐ Universitätsklinikum Düsseldorf
- ☐ Universitätsklinikum Erlangen
- ☐ Universitätsklinikum Essen
- ☐ Universitätsklinikum Frankfurt
- ☐ Universitätsklinikum Freiburg
- ☐ Universitätsklinikum Gießen und Marburg
- ☐ Universitätsmedizin Göttingen
- ☐ Universitätsmedizin Greifswald
- ☐ Universitätsklinikum Halle (Saale)
- ☐ Universitätsklinikum Hamburg-Eppendorf (UKE)
- ☐ Medizinische Hochschule Hannover
- ☐ Universitätsklinikum Heidelberg
- ☐ Hochschule Heilbronn
- ☐ Universitätsklinikum Jena
- ☐ Uniklinik Köln
- ☐ Medizinische Fakultät der Universität Leipzig
- ☐ Universitätsklinikum Magdeburg
- ☐ Universitätsmedizin Mainz
- ☐ Universitätsmedizin Mannheim
- ☐ Klinikum der Universität München (LMU Klinikum)
- ☐ Klinikum rechts der Isar TU München
- ☐ Helmholtz Zentrum München
- ☐ Universitätsklinikum Münster
- ☐ Universitätsklinikum Regensburg
- ☐ Universitätsmedizin Rostock
- ☐ Universitätsklinikum des Saarlandes
- ☐ Universitätsklinikum Schleswig-Holstein
- ☐ Klinikum Oldenburg
- ☐ Universitätsklinikum Tübingen
- ☐ Universitätsklinikum Ulm
- ☐ Universitätsklinikum Würzburg
- ☐ Universitätsklinikum OWL (Bielefeld)

For which Project are you answering the survey?

- ☐ AKTIN-EZV - Echtzeit-Versorgungsforschung mit dem AKTIN-Notaufnahmeregister (Abgeschlossene Projekte 2021)
- ☐ B-FAST - Bundesweites Forschungsnetz Angewandte Surveillance und Testung (Abgeschlossene Projekte 2021)
- ☐ CEO-SYS - Aufbau eines Covid-19 Evidenz-Ökosystems zur Verbesserung von Wissensmanagement und Translation (Abgeschlossene Projekte 2021)
- ☐ CODEX - COVID-19 Data Exchange Platform (Abgeschlossene Projekte 2021)
- ☐ COMPASS - Coordination on mobile pandemic apps best practice and solution sharing (Abgeschlossene Projekte 2021)
- ☐ COVIM - Bestimmung und Nutzung von SARS-CoV-2 Immunität (Abgeschlossene Projekte 2021)
- ☐ DEFEAT PANDEMICS -Deutsches Forschungsnetzwerk Autopsien bei Pandemien (Abgeschlossene Projekte 2021)
- ☐ EGEPAN UNIMED - Entwicklung, Testung und Implementierung von regional adaptiven Versorgungsstrukturen und Prozessen (Abgeschlossene Projekte 2021)
- ☐ METHODOCOV - Methodennetzwerk zur Unterstützung von Covid-19 Forschungsprojekten bei der Messung sozialer und kontextueller Faktoren (Abgeschl. Proj. 2021)
- ☐ ORGANO-STRAT - Organspezifische Stratifikation bei Covid-19 (Abgeschlossene Projekte 2021)
- ☐ PALLPAN - Nationale Strategie für Palliativversorgung in Pandemiezeiten (Abgeschlossene Projekte 2021)
- ☐ RACoon - Radiological Cooperative Network zur COVID-19 Pandemie (Abgeschlossene Projekte 2021)
- ☐ AKTIN@NUM - Betrieb der Infrastruktur des AKTIN-Notaufnahmeregisters (Aktuelle Projekte 2022)
- ☐ CODEX+ (Aktuelle Projekte 2022)
- ☐ GENSURV (Aktuelle Projekte 2022)
- ☐ NAPKON - Nationales Pandemie Kohorten Netz ((Abgeschlossene Projekte 2021 und Aktuelle Projekte 2022)
- ☐ NUKLEUS - Die NUM Klinische Epidemiologie- und Studienplattform (Aktuelle Projekte 2022)
- ☐ RACoon - Die Radiologie Kooperation im NUM (Aktuelle Projekte 2022)
- ☐ Other (Freitext Option)

If other, please specify

(Additional Information e.g Add link to data here:)

What data set are you evaluating with this survey?

In the following, the term "data" refers to the data processed/existing in your project in general. (e.g. software or documentation)

In the following, the term 'dataset' means: A dataset is a collection of related, discrete data that can be accessed individually or in combination, or that is managed as a whole.

- ☐ Organisational data (guidelines, workflows and the like)
- ☐ A data set
- ☐ A software
- ☐ Other

If other, please specify

(Additional Information e.g Add link to data here:)

Have you made a FAIR evaluation before?

- ☐ Yes
- ☐ No
- ☐ I don't know

Have you used a FAIR evaluation tool before?

- ☐ Yes
- ☐ No
- ☐ I don't know

Add tool name (and link) here:

(Optional)

What results did the tool provide?

(Add tool name (and link) here)

Have you made any changes after getting the results of the evaluation?

- ☐ Yes, changes proposed by the tool
- ☐ Yes, changes not suggest by the tool
- ☐ No

What changes did you make?

How do you document your data management activities?

- ☐ According to SOP(Standard Operating Procedure)
- ☐ Documentation via a data management plan/tool
- ☐ Other
- ☐ No documentation
- ☐ I don't know

Please name the standard:

If other, please specify

Does the data have any identifiers assigned?

- ☐ Local identifier
 - ☐ Web address (URL)
 - ☐ Globally Unique, citable and persistent (e.g. DOI, PURL, ARK, Handle)
 - ☐ Other
 - ☐ No identifier
 - ☐ I don't know
- (For the project you are answering)

If other, please specify

Does the metadata file contain links to the actual data they describe?

- ☐ Unknown (Yet)
- ☐ No
- ☐ Yes, using a unique identifier
- ☐ Yes, using another type of identifier (e.g. web address)
- ☐ I don't know

Please specify the type of identifier

Does the metadata have any identifiers assigned?

- ☐ Local identifier
- ☐ Web address (URL)
- ☐ Globally Unique, citable and persistent (e.g. DOI, PURL, ARK, Handle)
- ☐ Other
- ☐ No identifier
- ☐ I don't know

If other, please specify

Did you provide sufficient metadata (information) about your data for others to find, understand and reuse your data?

- ☐ No metadata
 - ☐ Minimal metadata but only required field
 - ☐ Required metadata fields and some additional fields
 - ☐ Rich metadata with as much information as possible
 - ☐ I don't know
- (Required metadata fields include, for example title, creator, date created, description, audience)

What type of repository or registry is the metadata record in?

- ☐ The data is not described in any repository
- ☐ Local institutional repository
- ☐ Domain-specific repository
- ☐ Generalist public repository
- ☐ Data is in one place but discoverable through several registries
- ☐ I don't know

Name the actual repositories in use please:

What additional documentation is made?

- ☐ Readme file
- ☐ Versioning
- ☐ Provenance
- ☐ Other
- ☐ I don't know

If other, please specify

How accessible is the data?

- ☐ No access to data or metadata
- ☐ Access to metadata only
- ☐ Unspecified conditional access e.g. contact the data custodian for access
- ☐ Embargoed access after a specified date
- ☐ A de-identified / modified subset of the data is publicly accessible
- ☐ Fully accessible to persons who meet explicitly stated conditions, e.g. ethics approval for sensitive data
- ☐ Publicly accessible
- ☐ I don't know

How is the data available online without requiring specialised protocols or tools once access has been approved?

- ☐ By individual arrangement
- ☐ File download from online location
- ☐ Non-standard web service (e.g. OpenAPI/Swagger/informal API)
- ☐ Standard web service API (e.g. OGC)
- ☐ No access to data
- ☐ I don't know

Which licences does your NUM (sub)project recommend to use?

- ☐ Open access (CC0)
- ☐ Restricted access
- ☐ Embargo
- ☐ My project management did not recommend any licences for use in the project context.
- ☐ Other access
- ☐ I don't know

If other, please specify

Which of the usage licenses provided did you choose in order to comply with the access rights attached to the data?

- ☐ Open access (CC0)
- ☐ Restricted access
- ☐ Embargo
- ☐ Other access
- ☐ No access
- ☐ I don't know

If other, please specify

What (file) format(s) is the data available in?

- ☐ Mostly in a proprietary format
- ☐ In a structured, open standard, non-machine-readable format
- ☐ In a structured, open standard, machine-readable format
- ☐ I don't know

What file format(s) do you use?

(examples: .csv, .xml, .tsv, .json, FHIR, etc.)

Are standard vocabularies, thesaurus or ontologies used in your project to enable interdisciplinary interoperability between well defined domains?

- ☐ Standardised vocabularies/ontologies/schema without global identifiers
- ☐ Standardised open and universal using resolvable global identifiers linking to explanations
- ☐ Other
- ☐ Data elements not described
- ☐ No standards have been applied in the description of data elements
- ☐ I don't know

If other, please specify

What kind of data standards are being used for semantic interoperability?

- ☐ There are no standards for my discipline
- ☐ free text option
- ☐ I don't know

If you selected free text, please specify here

(Examples: DICOM, SNOMED, LOINC, FHIR, ICD 9-10-11, ACT)

How is the metadata linked to other data and metadata (to enhance context and clearly indicate relationships)?

- ☐ The metadata record includes URI links to related metadata, data and definitions
- ☐ Metadata is represented in a machine readable format, e.g. in a linked data format such as RDF
- ☐ Other
- ☐ There are no links to other metadata
- ☐ I don't know

Please specify

Did you provide contextual information about your data?

- ☐ Persistent Identifier(s)
- ☐ Reference to other datasets
- ☐ Reference to publications
- ☐ Other
- ☐ No contextual metadata
- ☐ I don't know

If other, please specify

Why did you choose NOT to provide contextual information?

- ☐ No time
- ☐ No tools available
- ☐ I never thought about it before
- ☐ I don't know
- ☐ Other

If other, please specify

What kind of information did you provide about the provenance of your data?

- ☐ Origin of data
- ☐ Citations for reused data
- ☐ Workflow description for collecting data (machine readable)
- ☐ Processing history of data
- ☐ Version history of data
- ☐ Other
- ☐ No information
- ☐ I don't know

If other, please specify

How is the provenance data stored?

Do you already use any provenance tools?

- ☐ Yes
- ☐ No
- ☐ I don't know

Please name the tool:

Which of the following best describes the license/usage rights attached to the data?

- ☐ Non-standard text-based license
- ☐ Non-standard machine-readable license (clearly indicating under what conditions the data may be reused)
- ☐ Standard text based license
- ☐ Standard machine-readable license (e.g. Creative Commons)
- ☐ No license
- ☐ I don't know

Do you provide information on methods and tools that permit the understandability, integrity, value and readability of data intended to be kept on the long-term? (e.g. versioning, archival and long term reuse issue for protocols, softwares, required methods and contexts to create, read and understand data)

- ☐ Never
- ☐ If mandatory
- ☐ Sometimes
- ☐ Always
- ☐ I don't know

Do you feel knowledgeable enough to document and archive the data and results generated throughout NUM in a FAIR way to enable reuse and reproducibility of results beyond the current funding period?

- ☐ Yes
- ☐ No
- ☐ I don't know

Do you have any general feedback about the survey?
