



DZNE Research Data Management Policy

Version 1.0

Date: 1/14/2021

Deutsches Zentrum für
Neurodegenerative Erkrankungen e.V.
(DZNE) in der Helmholtz-Gemeinschaft

Address:
Venusberg-Campus 1/99
53127 Bonn

Tel +49 228 43302- 0
Homepage: www.dzne.de

1. Preamble

The German Center for Neurodegenerative Diseases (DZNE) and other Health Centers of the Helmholtz Gemeinschaft recognize the fundamental importance of research data¹ and its management in maintaining research excellence and scientific integrity, and are committed to pursuing the highest standards of research¹ practice. Recent developments such as computational advances, internationalization and data protection regulations present significant new opportunities and challenges in this regard.

The purpose of this policy is to provide a framework that defines the responsibilities of DZNE and its researchers¹, and to provide guidance for the proper management of research data throughout its full life cycle. This includes promoting data sharing and re-use to the widest extent feasible, in order to maximize research transparency, quality and impact.

The DZNE is committed to a goal of making data created as part of the research process compliant with the FAIR principles². Data should be: Findable, Accessible, Interoperable and Reusable. Implementation of this policy also aims to ensure conformity with the rules of funding bodies, pertinent legal obligations and ethical responsibilities including those in the:

- Helmholtz Gemeinschaft position paper³ and guidelines⁴ on research data management and research software⁵
- Guidelines of the Deutsche Forschungsgemeinschaft (DFG) for handling research data⁶ and good scientific practice⁷
- Bundesdatenschutzgesetz⁸
- EU Open Science Policy⁹
- EU General Data Protection Regulation¹⁰



Deutsches Zentrum für
Neurodegenerative Erkrankungen e.V.
(DZNE) in der Helmholtz-Gemeinschaft

Address:
Venusberg-Campus 1/99
53127 Bonn

Tel +49 228 43302- 0
Homepage: www.dzne.de

2. Jurisdiction

This policy was developed based on consensus discussion among working group members from the Helmholtz Health Centers, and was approved by the Health Research Board on November 20th 2020. It applies to all researchers active at the DZNE.

3. Intellectual Property Rights

Intellectual property rights and ownership determine the basic conditions for use and sharing of research data. The terms are defined in the contract between a researcher and DZNE, the DZNE's internal policies and legal regulations, and might also be governed through further formal agreements (e.g. those of funding agencies, collaborations and data repositories).

4. Handling Research Data

Researchers are strongly encouraged to develop a written Data Management Plan (DMP) at the design stage of each project, even when not specifically required.

Data storage

Research data must be stored in a correct, complete, unadulterated and reliable manner in order to preserve its integrity. Furthermore, data should be identifiable (including through use of persistent identifiers), accessible, traceable, interoperable, and whenever possible, available for subsequent use. All research data generated and elaborated at DZNE must be stored at DZNE, in the institutional archiving systems and according to institutional policies, with secure backup storage. Data may be published/shared in reliable trusted external repositories, in addition to the institutional storage, under written agreement. Appropriate written agreements should also always be concluded when incoming data from other institutions or repositories is to be stored at DZNE. Storage infrastructures should be compliant with best practices in the field.

Research data and related material should be retained for a minimum of ten years after acquisition or generation. When required, longer retention periods prevail (e.g. clinical trials, patents).

Data access and re-use

The DZNE supports access to research data following the European Commission for Open Data principle, "as open as possible, as closed as necessary."¹¹ This includes not only the data/data set itself, but also elements such as metadata¹, methods, protocols and

software/code needed to support effective data use. The use of open-source software/code to support analysis is strongly encouraged.

When licensing is indicated to allow data sharing¹ and re-use, the data should be made available under an open license, unless legal obligations, third party rights, intellectual property rights and privacy rights preclude this (e.g. Creative Commons¹² and licenses approved by the Open Source Initiative¹³).

In publications and any other presentations of data, the data sources (original and subsequently-used) must be acknowledged and traceable.

Data deletion

Deletion or destruction of research data and records, either after expiration of the retention period or for specific legal or ethical reasons, must be carried out considering contractual obligations of third party funders and other stakeholders, including collaboration partners. Such actions should be documented and be accessible for future audit. Backup data copies should also be deleted.

5. Responsibilities, Rights and Duties

Researchers/research data producers are responsible for:

- a) Management of research data and data sets through their life cycle in adherence with principles and requirements expressed in DZNE policies;
- b) Definition of the DMPs including responsible person(s); general responsibilities and decisions (e.g. about sharing/access, central storage of data, quality of content, definition of formats). This responsibility lies with the Principal Investigator(s) generating the data.
- c) Allocation of appropriate resources (time and financial resources) for data management in grant proposals;
- d) Collection, documentation/curation, archiving, access to and storage or proper destruction of research data and research-related records. This also includes the definition of protocols and responsibilities within a joint research project. Such information should be included in a DMP, as well as in protocols that explicitly define the collection, administration, integrity, confidentiality, storage, use and publication of data that will be employed;
- e) Compliance with the general requirements of the funders and the research institution;



Deutsches Zentrum für
Neurodegenerative Erkrankungen e.V.
(DZNE) in der Helmholtz-Gemeinschaft

Address:
Venusberg-Campus 1/99
53127 Bonn

Tel +49 228 43302- 0
Homepage: www.dzne.de

- f) Planning to enable, wherever possible, the continued use and sharing of data even after project completion. This includes defining post-project usage rights, with the assignment of appropriate licenses, as well as the clarification of data storage and archiving in the case of discontinued involvement or the researcher(s) at the DZNE;
- g) Acknowledgment of data sources and abiding by the terms and conditions under which original data was accessed.

The DZNE is responsible for:

- a) Providing its researchers and research groups with a basic research infrastructure that includes tools and services for supporting the management, use, findability and sharing of data as well as with the capacity for appropriate storage, preservation, computing and processing;
- b) Providing support, training, guidance and advice on research data management starting from planning to execution and thus enable researchers to exercise their responsibilities outlined above and to comply with requirements of third party funders and other legal entities;
- c) Supporting retention of research data sets and related metadata and software in the appropriate format, in line with its agreed policy and those of its research funders;
- d) Supporting the identification and resolution of legal and ethical issues related to research data.

6. Version/Validity

This policy (version 1.0) will be reviewed and updated as needed, by the Executive Board of the DZNE.

7. Definitions ^{14, 15}

Research is any creative and systematically performed work with the goal of furthering knowledge, including discoveries regarding people, culture and society, in addition to the use of such knowledge for new applications.

Researchers refers to all members of an institution including employed scientists, students and support staff as well as others with a formal affiliation at DZNE, who have access to, generate and/or manage research data. Visiting researchers or collaborators may also be expected to comply with the policy.

Research data refers to all information (independent of form or presentation) needed to support or validate the development, results, observations or findings of a research project, including contextual information. Research data include all materials that are created in the course of academic work, including digitization, records, source research, experiments, measurements, surveys and interviews. This includes methods/protocols, metadata, software and code. Research data can take on several forms: during the lifespan of a research project, data can exist as gradations of raw data, processed data (including negative and inconclusive results), shared data, published data and Open Access published data, and with varying levels of access, including open data, restricted data and closed data.

Metadata is data providing information about data that makes findable, trackable and (re)usable. It can include information such as contact information, geographic locations, details about units of measure, abbreviations or codes used in the dataset, instrument and protocol information, survey tool details, provenance and version information and much more.

Data sharing is the practice of making scientific data used for scholarly research available to others, for research re-use or in knowledge transfer activities (e.g. researchers, institutions, the broader public).

8. References

The general outline and some text in this policy were adopted from the resources of the LEARN Project (<http://learn-rdm.eu/en/learn-policies-and-data-management-plans/>).

1. See Section 7, Definitions
2. Wilkinson, M., Dumontier, M., Aalbersberg, I. et al. The FAIR Guiding Principles for scientific data management and stewardship. *Sci Data* 3, 160018 (2016).
<https://doi.org/10.1038/sdata.2016.18>
3. „Die Ressource Information besser nutzbar machen!“, Positionspapier zum Umgang mit Forschungsdaten in der Helmholtz-Gemeinschaft, adopted by AK-Open Science on September 22, 2016
https://www.helmholtz.de/fileadmin/user_upload/01_forschung/Open_Access/DE_AKOS_TG-Forschungsdatenleitlinie_Positionspapier.pdf (Access February 2020)
4. Empfehlungen für Richtlinien der Helmholtz-Zentren zum Umgang mit Forschungsdaten. In der 109. Mitgliederversammlung der Helmholtz-Gemeinschaft am 13.-14.

- September 2017 beschlossen, Potsdam, 14 p.
<https://doi.org/10.2312/os.helmholtz.002>
5. Empfehlungen zur Implementierung von Leit- und Richtlinien zum Umgang mit Forschungssoftware an den Helmholtz-Zentren: Positionspapier. (2019): Potsdam: Helmholtz Open Science Office, 11 p. <https://doi.org/10.2312/os.helmholtz.008>
 6. Umgang mit Forschungsdaten – DFG-Leitlinien zum Umgang mit Forschungsdaten, adopted by the Senate of the DFG on September 30, 2015; last update on 30.10.2020.
https://www.dfg.de/foerderung/antrag_gutachter_gremien/antrags_tellende/nachnutzung_forschungsdaten/index.html
 7. Gute wissenschaftliche Praxis, DFG Leitlinien, last update on 06.07.2020
https://www.dfg.de/foerderung/grundlagen_rahmenbedingungen/gwp/
 8. Bundesdatenschutzgesetz, Bundesministerium der Justiz und für Verbraucherschutz, http://www.gesetze-im-internet.de/bdsg_2018/
 9. EU Open Science Policy, last update on 29.10.2020.
<https://ec.europa.eu/digital-single-market/en/open-science>
 10. EU General Data Protection Regulation (GDPR), <https://gdpr-info.eu/> (Access February 2020)
 11. Data management - H2020 Online Manual.
https://ec.europa.eu/research/participants/docs/h2020-funding-guide/cross-cutting-issues/open-access-data-management/data-management_en.htm (Access February 2020)
 12. Creative Commons <https://creativecommons.org/licenses/>
(Access February 2020)
 13. Open Source Initiative (OSI), <https://opensource.org> (Access February 2020)
 14. LEARN Toolkit of Best Practice for Research Data Management.
<http://learn-rdm.eu/en/research-data-management-toolkit-now-available/> (Access February 2020)
 15. OpenAIRE – “What is metadata for research data?”
<https://www.openaire.eu/what-is-metadata> (Access February 2020)