

Before gaining access to the Datasets of DZNE, the Approved User shall have to accept these additional terms and conditions by placing a checking mark in the box 'I accept the Additional Terms and Conditions DZNE', which contains a link thereto.

Additional terms and conditions for DZNE – Datasets

Dataset Name: EPND

Cohort Owner: Deutsches Zentrum für Neurodegenerative Erkrankungen e. V. (DZNE)

Dataset Type: Standard Dataset or Protected Dataset
Data can only be shared upon approval of a research proposal, all positive votes from the competent ethic committee/s as part of the data request and the approval of the cohort owner, DZNE

Brief Description of the Dataset:

Data is collected as part of the European Platform for Neurodegenerative diseases (EPND) project, including a mixed cohort of individuals with Alzheimer's disease, Parkinson's disease, Lewy Body Dementia and controls recruited from several European studies. The dataset contains biomarker data, demographic data, cognitive and neuropsychological test results, standardized clinical and motor rating scales, genetic data, imaging data, and sample related information.

Additional Terms:

Datasets can only be used for internal non-commercial research purposes. Were commercial use of data is legally permissible pursuant to the informed consent of relevant data subjects, DZNE and the Approved User, entirely at the discretion of DZNE, may conclude a separate agreement on such use. Datasets remain the property of DZNE at all times.

The conditions for using the DZNE Dataset are as follows:

Permission:

- Permission shall be given for a particular (defined) purpose and the use of the dataset is limited to that use only,
- Permission shall be given for a period of 2 years and the use of the dataset is limited to that period; for an extended period of use a new application must be submitted,
- DZNE as the cohort owner is entitled to withdraw the permission at any time

Use:

- Use, activities and / or conduct that in any way conflicts with currently applicable legislation or regulations, public order and / or common decency is prohibited;
- The right to use the DZNE-dataset is not transferable from the Approved User to a third party
- No data shall be copied for, or provided to other researchers who are not directly under the supervision of the Approved User. The discloser of data to affiliated companies or service providers for the approved research project is permitted, provided that they are contractually bound to comply with the obligations set out in this submission form.

Reporting Obligations:

- The Approved User shall report to the DZNE (Klinische-Studien@dzne.de), on request, regarding the progress and results achieved in the research project
- Within a maximum of 1 year following the end of the research project's term (cf. the request), the Approved User shall send to the DZNE (Klinische-Studien@dzne.de) a final report on the research project.

Intellectual property rights:

- The Approved User is entitled to all rights to results obtained via use of data; The Approved User grants the DZNE, for purposes of its own internal research and development, a non-exclusive, non-transferable, irrevocable and royalty-free right to use the results, including intellectual property right ("Schutzrechte")
- The Approved User shall inform the DZNE, without special request, without delay and in writing (Technologietransfer@dzne.de), regarding any inventions related to the data obtained via this submission form. The Approved User and DZNE shall negotiate and conclude a separate formal agreement, regarding the DZNE's possible joint ownership of such inventions and their commercialization.

Publications:

- At least 30 days prior to their submission for publication, all publications shall be submitted to the DZNE (Klinische-Studien@dzne.de) for evaluation. Within a period of 30 days, the DZNE may demand co-authorship or object to the publication for important reasons ("aus wichtigem Grund"). In particular, the important reasons in this context include the threat of pre-release of patentable results; this shall apply, however, only until a priority-establishing patent request (provisional patent application) has been filed, and for no longer than additional 90 days following the DZNE's objection to publication. If the DZNE identifies patentable results, it may propose changes to the publication that rule out the possibility of any pre-release. If the DZNE does not object within 30 days after the draft of the publication has been sent to it, the publication may be published.
- The DZNE reserves the right to be named as a co-author in cases where such mention is appropriate according to the rules of good scientific practice.
- The following acknowledgement of the DZNE's serving as the data source shall be included in all publications that refer to the research project: "The data were provided by the study group "XYZ – to be filled out by the DZNE" of the Clinical Research of the German Center for Neurodegenerative Diseases (DZNE)"
- Once the publication has been published, the Approved User shall promptly provide the DZNE with a specimen copy.

Deletion of Data:

- Upon termination of the right to use data, and regardless of the reason for such termination, and upon request by DZNE due to the obligation to delete data according to data protection regulation, the Approved User shall return to the DZNE, without delay, all original data-storage media in its possession and delete any copies of data that have been made.
- Without any further request, the Approved User shall confirm to the DZNE (Data.ManagementKF@dzne.de), in writing, that it has fulfilled these obligations.

Confidentiality

- The Approved User promises, for a period of 5 years after receipt of data, to treat the information and DATA exchanged as confidential and not to make it available to any third parties.
- This shall not apply to information and data for which the recipient is clearly able to demonstrate by documentary evidence (a) that were already known to the recipient, (b) that were already publicly known or that became publicly known through no fault of the recipient, (c) that, demonstrably, have been independently generated by the recipient, (d) that are made available to the recipient by a third party authorized for such disclosure, or (e) that have to be disclosed due to regulatory or judicial order or due to mandatory statutory provisions.

Liability

- The provided data may contain errors or defects. The DZNE assumes no responsibility for the correctness, completeness (including completeness in number), consistency or accuracy of the provided data or for the suitability of data for any specific purpose.
- The DZNE is liable for any damage caused intentionally ("*Vorsatz*") or by gross negligence ("*grobe Fahrlässigkeit*"). In the case of damages caused by simple negligence ("*einfache Fahrlässigkeit*"), the DZNE shall only be liable for breach of a material contractual obligation ("*wesentliche Vertragspflicht*") limited to the amount of the typical and foreseeable damage ("*typischer und vorhersehbarer Schaden*") at the time this AGREEMENT was concluded. The above restrictions and exclusions of liability shall not apply in the event of death, injuries or damage to health, or in the case of claims under the Product Liability Act ("*Produkthaftungsgesetz*").
- The Approved User`s liability for damages incurred by DZNE, especially damages resulting from illegal or unauthorized use of data, including but not limited to fines resulting from a breach of data protection regulation, shall be governed by statutory liability.

Data protection

- DZNE affirms that, to the extent the Dataset provided hereunder is a Standard Dataset, it has been de-identified, and contains no Personal Data, or personal health information (PHI), or other information subject to any heightened obligations for the collection, storage, processing, transmission or use thereof.
- To the extent DZNE delivers a Protected Dataset, the data transfer from DZNE to ADDI Workbench and the transfer from Workbench to Approved Users will only take place by accepting the Personal Data Protection Agreements according to Appendix B of the Data Contributor Agreement.

EPND data use conditions

A. Outcome policies

For any outcome (conference abstracts, posters, presentations, publications) using the requested EPND data, please follow the below policies:

Conference Abstract:

- Conference abstracts should be sent **at least 1 week prior to submission** to co-authors and to the EPND management office (pmo@epnd.org). Failure to respond will be taken as agreement.

Poster / presentations:

- Posters and presentations should be sent **at least 1 week prior to presentation** to co-authors and the EPND management office (pmo@epnd.org). Failure to respond will be taken as agreement.
- EPND and Innovative Health Initiative (IHI) logos should be included in all posters and presentations (see section C – EPND consortium)

Scientific publication:

- If a scientific publication is planned, a detailed abstract should be shared at the start of the project with WP5 leads.
- Publication drafts should be sent **at least 2 weeks prior to submission** to co-authors and to the EPND management office (pmo@epnd.org).

Information on co-authors to be included can be found in sections B, C and D.

B. Co-Author Guidelines

An overview of the co-author guidelines is provided below. Please see section C for names and affiliations. **Please see section D to know which EPND co-authors you should include** (pre-compiled co-author lists) **depending on used dataset(s)**.

1. **First author:** Conducted the analysis and wrote the manuscript / corresponding author

2. **Additional authors:** All individuals substantially involved in the data analysis, project conception or design, drafting of manuscript, data interpretation, critical revisions, or intellectual contributions.
3. **EPND contributors:** sample analysis, disease area specialists, harmonization team, aliquoting team, ethic and legal aspect team, cohort owners, study leads as applicable.
4. **The EPND consortium.** - A more detailed list of contributors can be included in the acknowledgments or MEDLINE listings.

The IHI/EFPIA funding acknowledgement should be included in all presentations and publications (see section C – EPND consortium)

EPND data also include participants from the German center for neurodegenerative diseases (DZNE). **To know which DZNE members should be included in the co-author list**, please reach out to Marie

Theres Kronmueller (MarieTheres.Kronmueller@dzne.de) with the list of “epnd_id” that you included in your study.


C. EPND co-author information

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EPND consortium:

Checklist	Publication type	To add
IHI JU Acknowledgement	All	<p>“The EPND project has received funding from the Innovative Health Initiative 2 Joint Undertaking under grant agreement No 101034344. This Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA.”</p> <p>or</p> <p>If the character count of the journal article/abstract does not allow the full acknowledgement to be used, the following phrase is permitted:</p> <p>“This work has received support from the EU/EFPIA Innovative Health Initiative Joint Undertaking (EPND, grant No 101034344)”</p>
Link to IHI website	All	“www.ihp.europa.eu”
Disclaimer	All	“This communication reflects the views of the EPND consortium and neither IHI nor the European Union and EFPIA are liable for any use that may be made of the information contained herein.”
Logos EPND, EU, EFPIA, IHI	Presentations, posters, press releases	 <p>The image displays four logos stacked vertically. From top to bottom: the EPND logo in green stylized lowercase letters; the flag of the European Union (blue with yellow stars); the EFPIA logo in blue lowercase letters with an orange asterisk above the 'i'; and the IHI logo, which consists of three green vertical bars of varying heights and two black dots, followed by the text 'innovative health initiative' in a dark blue sans-serif font.</p>
EPND consortium affiliation	Journal publications	Add “The EPND Consortium [1]” as author in the authors list with affiliation [1] being www.epnd.org or

Add “on behalf of the EPND Consortium [1]” (at the end or below the authors list) with affiliation [1] being www.epnd.org

D. Pre-compiled co-author name lists

For studies using only EPND ATN study data:

1. **First author and additional authors involved** in the manuscript (can also be last authors)
2. **The following list:**

Henrik Zetterberg, Gwendlyn Kollmorgen, Pieter Jelle Visser, Stephanie J. B. Vos, Marianna Rizzo, Rejko Krüger, Sara Beatriz Gomes Fernandes, Dag Aarland, Ann-Cecilie Hopøy, Charlotte E. Teunissen, Davit Chokoshvili, Jort E. G. B. Vijverberg, Afin W. Lemstra, Betty M. Tijms, [*up to 6 DZNE co-authors, see above*], Giovanni B. Frisoni, Jakub Hort, Zuzana Nedelska, Tormod Fladby, Sophie Mutel, Rajaraman Krishnan, on behalf of the IHI EPND consortium

For studies using EPND Complement Biomarker Study Milliplex data:

1. **First author and additional authors involved** in the manuscript (can also be last authors)
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For studies using EPND Complement Biomarker Study Olink 3072 data:

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For studies using EPND Complement Biomarker Study Somascan 7k data:

1. **First author and additional authors involved** in the manuscript (can also be last authors)

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