

Data Protection Notice for the Use of the LabForward as an Electronic Laboratory Notebook



The *German Center for Neurodegenerative Diseases e. V. (DZNE)*, based on the Venusberg-Campus 1/99, 53127 Bonn/Germany, intends to process the personal data of employees that create an account to use the Electronic Laboratory Notebook software of LabForward (LabFolder, LabRegister products), for recording primary research data with full audit trail. DZNE's LabForward instance is only available to DZNE users (with DZNE email addresses). Research data are accessible only to the account owner and the respective DZNE Research Group Leaders, unless they are explicitly shared or access permissions are granted exceptionally to others DZNE users. DZNE IT staff may need to access the data for resolution of technical problems or to enable researchers the access to the software.

As specified on the web site to access LabForward (<https://labbook.dzne.de/elN/access/login>), and in the data protection notice below, personal data are collected when signing up for an LabFolder account. The personal data are not shared with LabForward or any third party. Internally, the data are distributed to DZNE to staff involved directly in managing the software (IT and Scientific Strategy Office), and are handled confidentially as required by DZNE rules.

I have read and understood the enclosed information on data protection. By registering to use LabForward, I agree to the processing of my data by DZNE. I may withdraw my consent without justifying this decision.

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Information on data protection

Controller pursuant to the General Data Protection Regulation and other national data protection laws as well as other provisions on data protection law

Deutsches Zentrum für Neurodegenerative Erkrankungen e. V. (DZNE), Venusberg- Campus 1/99, 53127, Bonn/Germany, tel.: +49 228 43302-0, e-mail: information@dzne.de, website: www.dzne.de, represented by Professor Pierluigi Nicotera MD, PhD (Scientific Director and Chairman of the Executive Board) and Dr Sabine Helling-Moegen, LL. M. (Executive Assistant).

Description and scope of data processing

In order to provide access to use the software LabForward (LabFolder / LabRegister) we process the following personal data: first name, surname, e-mail address and research group. In addition, the processing also covers primary research data, its metadata and related data such as research plans, methods and protocols. DZNE registrants and users of LabFolder will be informed about changes concerning LabForward, such as software upgrades, implementation of additional functions, trainings etc. by e-mail by DZNE staff managing the software. We do not process personal data to make automated decisions, including profiling, or to monitor the performance of data subjects.

Legal basis for data processing

The legal basis for the processing of personal data is a declaration of consent according to Article 6 (1) lit. a of the EU-GDPR.

Duration of storage

Personal data is generally erased after the data subjects withdraw their consent, or its processing is restricted as soon as it is no longer necessary to achieve the purpose for which it was retained. The data may be retained for longer if the European or national legislator stipulates such retention in the relevant EU regulations, laws or other rules that we are subject to or if there are compelling legitimate grounds for processing that overrule the interests, rights and freedoms of the data subject or if processing is carried out to assert, exercise or defend legal claims.

Withdrawal and erasure option

Data subjects may withdraw their consent to the processing of their data at any time and without needing to justify their decision. Your withdrawal of consent must be addressed to:

Deutsches Zentrum für Neurodegenerative Erkrankungen e. V. (DZNE), Data Protection Manager, subject: "LabForward", Venusberg-Campus 1/99, 53127 Bonn/Germany.

Your other rights

You may ask us for information as to whether we process your personal data. You have the right to request that we rectify and/or complete your personal data that has been processed by us, if it is incorrect or incomplete. We shall forthwith proceed to rectify the data. Under certain statutory conditions you may request the restriction of the processing of your personal data. If processing has been restricted in line with the above requirements, you shall be informed by us before the restriction is lifted. You have the right to object to the processing of your personal data. In such a case, we will no longer process your personal data unless we can cite compelling legitimate reasons for the processing that overrule your interests, rights and freedoms or if processing is carried out in order to assert, exercise or defend legal claims. You have the right to receive your personal data that you have provided us with, in a structured, commonly used and machine-readable format or make us transmit your personal data directly to another controller as far as this is technically feasible. Such actions must not impair the freedoms and rights of other persons. You have the right to submit a complaint to a supervisory authority, in particular in the member state where you reside, work or where the alleged breach has taken place if you are of the opinion that the processing of your personal data is in breach of the GDPR of the EU.

The supervisory authority for data protection responsible for the DZNE

The Federal Officer for Data Protection and Freedom of Information, Graurheindorfer Str. 153, 53117 Bonn, Deutschland, Telefon: +49 228 997799-0

Contact data of the Data Protection Officer of the DZNE

Deutsches Zentrum für Neurodegenerative Erkrankungen e. V. (DZNE), Department for Data Protection, Venusberg-Campus 1/99, 53127 Bonn, Germany, telephone: +49 228 43302-430, e-mail: datenschutz@dzne.de