

NCER-PD data and biomaterial access request

PREAMBLE

The NCER-PD Consortium is willing to share its available data and biomaterial with internal project partners and external cooperation partners from universities, public research institutes and private partners for relevant research questions. Access to data, biomaterial, and associated information can only be granted upon a favorable decision by the NCER-PD Data and Sample Access Committee (Executive Committee and Program Committee). The data request should be legitimate, addressing sound research questions and will help in advancing the research field.

By submitting this access request, the requesting party agrees to comply with the following guidelines:

1. Usage Limitations: The data and/or samples can only be used for the analyses proposed and defined within this request. Any new analyses or objectives require a new request and prior approval from the Data and Sample Access Committee.
2. Data Protection: The provided data must not be shared with any third party without prior written consent from the NCER-PD Consortium.
3. Data Return Requirements:
 - All analyzed data or results derived from the provided samples must be shared with the NCER-PD Consortium
 - For biomaterial requests: excess biomaterial must be returned to the Consortium
4. Publication Requirements:
 - All scientific articles resulting from these analyses must adhere to the NCER-PD consortium publication guidelines
 - The NCER-PD Consortium has to be listed as co-author as appropriate and the latest version of the member list must be requested prior to submission to ensure up to date acknowledgments
 - All manuscripts must be reviewed by the NCER-PD Executive Committee (request.ncer-pd@uni.lu) prior to submission, with one week allowed for response
5. Compliance Requirements:
 - The requesting party is responsible for strictly following ethical standards and GDPR requirements
 - All reported data and results must be accurate
 - The project must have secured funding prior to sharing of biomaterial

The proposed research question will be evaluated for its scientific relevance, scope, and feasibility by the NCER-PD Executive Committee as a basis for the decision to approve access to the requested biomaterial and/or data. Then, the request will be evaluated by the NCER-PD Program Committee for the final decision.

In addition to this access request, the NCER-PD Consortium members and external cooperation partners shall enter into a separate material/data transfer agreement or a collaboration agreement with the owner(s) of such biomaterial and associated information to be granted access to NCER-PD biomaterial, data and associated information.

Taking into consideration that all program biomaterial is unique and available in limited quantities, only the number and scope of biomaterial essential to the project described in this request will be provided. Expenses arising from the provision of the biomaterial will be discussed on a cooperation basis, and the requesting party must cover the cost of the shipment.

HOW TO APPLY

Please do not exceed a total of 2 pages for the proposal part below. English language is mandatory. Please send this access request form to request.ncer-pd@uni.lu.

Request for NCER-PD data and biomaterial

Requesting party details			
Requestor name <i>if different from project PI</i>		Requestor email and affiliation <i>if different from project PI</i>	
Project Principal Investigator (PI)		Project PI affiliation	
Project PI position		Project PI email	
Cooperation aspects of the PI with NCER-PD team members <i>If applicable</i>		Name of NCER-PD team member involved <i>If applicable</i>	
Researcher(s) who will access biomaterial/data		Date	

Project details
Title of the research project
Background and objectives (5-10 lines)
Study methods and analysis (1/2 pages max.)
Funding information
Did the research project receive approval for the proposed use, e.g., from an ethics committee? <i>Please submit a copy of the approval with this form when applicable.</i>
Estimated end date of the study
Samples and data request details
Sample selection criteria, groups, and numbers per group <i>Please specify selection criteria (e.g., age, disease duration, etc.), groups (e.g., PD, healthy control, RBD, etc.) and the number per group. Include the justification for the number of samples requested.</i>

Details of biomaterial requested				
<i>Please provide the type, number and quantity of samples requested and any specific clinical parameters.</i>				
Type	Material	Numbers	Volume or concentration	Other
Biofluids	<input type="checkbox"/> EDTA plasma <input type="checkbox"/> CPT plasma <input type="checkbox"/> Serum <input type="checkbox"/> CSF supernatant <input type="checkbox"/> Lysed buffy coat <input type="checkbox"/> Whole blood <input type="checkbox"/> Urine supernatant	<i>n = # per group/ timepoint</i> <i>n = # per group/ timepoint</i> <i>n = # per group/ timepoint</i> <i>n = # per group/ timepoint</i> <i>n = # per group/ timepoint</i> <i>n = # per group/ timepoint</i> <i>n = # per group/ timepoint</i>	V= ... ml V= ... ml V= ... ml V= ... ml V= ... ml V= ... ml V= ... ml	
DNA/RNA	<input type="checkbox"/> DNA <input type="checkbox"/> RNA	<i>n = # per group/ timepoint</i> <i>n = # per group/ timepoint</i>		
Cells, tissue, material	<input type="checkbox"/> Viable PBMCs <input type="checkbox"/> Stool <input type="checkbox"/> Urine pellet <input type="checkbox"/> CSF pellet	<i>n = # per group/ timepoint</i> <i>n = # per group/ timepoint</i> <i>n = # per group/ timepoint</i> <i>n = # per group/ timepoint</i>	cells = ... gram = ... g	
Skin biopsy	<input type="checkbox"/> Fibroblasts	<i>n = # per group/ timepoint</i>		
Details of data requested				
<i>Please provide the type of data requested in detail.</i>				
Type	Data type	Specifics	Other	
Clinical data	<input type="checkbox"/> Descriptive <input type="checkbox"/> Diagnosis <input type="checkbox"/> Cognitive tests <input type="checkbox"/> MDS-UPDRS <input type="checkbox"/> Other			
Sensors data	<input type="checkbox"/> Gait			
Genetic data	<input type="checkbox"/> Specific gene annotations (GBA, LRRK2, PRKN) <input type="checkbox"/> GWAS (Neurochip) <input type="checkbox"/> Sequence (GBA) <input type="checkbox"/> WGS (data from 80 participants)	<i>List mutations for specific genes</i> <i>Describe data types needed</i>		

MRI (data from 130 participants)	<input type="checkbox"/> FLAIR <input type="checkbox"/> fMRI <input type="checkbox"/> QSM <input type="checkbox"/> TSE		
Metabolomics			
Microbiome	<input type="checkbox"/> 16S		
Name and signature of authorized representative of requesting party			
Signature			
Name			
Title			
Date			

To be completed by the NCER-PD team:

Proposed mode of cooperation (MDTA, CA, other)	
List of NCER-PD members who must be acknowledged in publications from this request	
Access request decision and date	
NCER-PD Executive Committee	
Name of authorized representative	
Title	Coordinator
Signature	
NCER-PD Program Committee	
Name of authorized representative	
Title	Coordinator
Signature	