

Biomedical Research Advisory Panel (BRAP) Application form to request for access to MND Collections Samples and Data

Please fully complete and sign the application form and return, along with supplementary information to:

The MND Collections Team

Email: mndcollections@mndassociation.org

Before completing the form please read the *MND Collections Terms and Conditions_v1.3 Jan 2021* that was sent along with this application form. Key clauses to refer to as part of this application are given in brackets in some of the questions below.

1. Title of Project (including MND Collections Project number):

Name of all applicants, affiliations and contact details:

2. Principal Applicant

a. Preferred Title:

b. Forename(s):

Surname:

3. Contact Details

a. Department:

b. Institution:

c. Address:

d. Telephone No:

e. Email:

4. Co-applicants (please duplicate if there are more than two applicants)

a. Preferred Title:

b. Forename:

Surname:

c. Department:

d. Institution:

e. Address:

f. Telephone No:

g. Email:

Project Details

- 5. Planned/known source of funding, eg MRC.** Please include decision dates for applications pending and grant references (*see paragraphs 3.1-3.6 and 3.9-3.12 of the MND Collections Terms and Conditions_v1.3 Jan 2021*)
- 6. Has the research proposed been subjected to peer review?**
If yes please provide details, eg funding body etc. (*see paragraphs 3.7 and 3.8 of the MND Collections Terms and Conditions_v1.3 Jan 2021*)
- 7. Does the study have Ethics Committee approval?**
If yes, please give the reference number and date of approval (*see paragraphs 3.13 -3.15 of the MND Collections Terms and Conditions_v1.3 Jan 2021*)
- 8. Please give a brief description of the project** (max 1000 words, covering the topics below)
- a. Background
 - b. Objectives
 - c. Research Question
 - d. Study Design
 - e. Cohort Definition
 - f. Method of Analysis
 - g. Justification for use of the MND Collections data
- 9. Please give details of the anticipated start date for the analysis of the data / start of the project**
- 10. How long will the project take to complete from receipt of data?**

Requested Sample Details

11. Details of the samples you are applying to use

Please complete the table with the numbers and type of sample you are applying to use (e.g. *person with MND, 150 DNA samples*).

Type of Sample	Genomic DNA from CIGMR	Familial Cell Lines from ECACC	Sporadic Cell Lines from ECACC	Other *
Person living with MND				
Control				
Other participant type *				
Total number of samples				

* Please see the MND Collections Terms and Conditions_v1.3 Jan 2021 for more details

12. Sample selection. If known, please provide a list of sample IDs for each sample type being requested in an appendix. If not known, please provide inclusion/exclusion criteria for sample selection.

13. Additional information on sample selection. Please provide as much information as possible regarding sample selection, eg if chosen more than one sample type, are the same sample IDs required? If requesting DNA, what concentration and amounts?

Clinical data accompanying the samples

All samples will be accompanied by the **minimum dataset**. Further information, referred to here as the extended dataset, has also been collected. Please see paragraphs 10.5 to 10.8 of the MND Collections Terms and Conditions_v1.3 Jan 2021 for more information.

Researchers wishing to access the additional phenotypic data from the extended dataset must first liaise with principal investigators from the MND Collections (Professor Chris Shaw, Professor Ammar Al-Chalabi, Professor Dame Pamela Shaw or Professor Karen Morrison) to explore collaborative opportunities. However, formal collaboration may not be required for access to the extended dataset.

Please note that these data were acquired from participants where possible, it is not a complete dataset for all participants. Thus, if you require data from the extended dataset in order to use all of the data from the participants that you are requesting, the data available from the extended dataset may restrict the number of participants data that will be available.

14. Do you require access to data from within the Extended Dataset?

(If **yes**, please complete Q14 and Q15. If **no**, please go to Q16)

15. Please give details of the discussion with the PIs regarding collaboration to use the extended dataset.

16. Please specify below the fields you require; the rationale for doing so and the order of priority in which these are useful, where 1 is the top priority.

Priority order	Name of Extended Dataset Data Field	Rationale for the use of this data field
Priority 1		
Priority 2		
Priority 3		
Priority 4		
Priority 5		
Priority 6		

17. Do you require access to data within the Epidemiology dataset?

If **Yes**, please complete the table below.

Name of Epidemiology Dataset Data Field

18. Declaration

I have read the UK MND Collection Terms and Conditions for Use and agree to abide by them and any amendments which may subsequently be issued. I shall be actively engaged in, and in day to day control of the project.

I agree to allow the Motor Neurone Disease Association to hold the details contained on this form in their records and for these details to be released to the Biomedical Research Advisory Panel and other appropriate bodies.

Signature:

Name:

Date:

19. Declaration

I have read the UK MND Collection Terms and Conditions for Use and agree to abide by them and any amendments which may subsequently be issued. I shall be actively engaged in, and in day to day control of the project.

I agree to allow the Motor Neurone Disease Association to hold the details contained on this form in their records and for these details to be released to the Biomedical Research Advisory Panel and other appropriate bodies.

Signature:

Date: