**MSBase Registry**

 **FORM: Request to access the global dataset**

This form is to be used to request access to data contained in the global dataset. It should be completed by persons eligible to access the global dataset including MSBase PI, SLG delegate, and MD or delegate. The completed form should be emailed to info@msbase.org. The request will undergo a preliminary feasibility review by the MSBase MD to ensure that it meets the standard required of the committee and that it does not directly conflict with other projects currently in progress. It will then be reviewed by the SLG Research Committee (SLG-RC).

MSBase will provide data preparation for the analysis and limited statistical advice (if requested) as part of our free member services for all approved projects.

Additionally, a limited number of projects will be approved for central statistical analysis performed by Dr Tim Spelman. If you wish to apply for statistical support, use the ***FORM: MSBase access to scientific review and/or statistical support request.***

**\* CONFIDENTIAL \***

# Project code (office use only): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

# Data requester

**Tick one box: MSBase PI** [ ]  **; SLG delegate** [ ] **; MD or delegate** [ ]

Name:

Click here to enter text.

Primary contact for this request (name and email):

Click here to enter text.

If PI, MSBase Centre name and code:

Click here to enter text.

# Project title

Click here to enter text.

# Synopsis

Click here to enter text.

# Purpose of access to data

Data analysis for scientific publication Yes [ ]  No [ ]

Data analysis for Pharma sponsored contract Yes [ ]  No [ ]

Other (please specify)

Click here to enter text.

# Other members of the team /collaborators who will have access to the raw data (name, position and email)

1. Click here to enter text.
2. Click here to enter text.

# If a Pharma sponsored contract, enter name of pharma company and contact who will receive the analysis report

Click here to enter text.

# Patient inclusion criteria for the analysis

Click here to enter text.

# Data variables required

Do you require the MSBase minimum dataset (see Appendix 1)? Yes [ ]  No [ ]

If extra variables are required, specify:

|  |
| --- |
| [ ]  Paraclinical tests  |
| [ ]  Relapses |
| [ ]  Treatments |
| [ ]  Medical history |
| [ ]  Safety data |
| [ ]  Covid-19 data |
| [ ]  Pregnancy data |
| [ ]  MRI registry data (scan date, number of lesions, new lesions etc) |

# Data from the MSBase Imaging Repository (MSBIR) – currently only available to MSBase PIs who are participating in the MSBIR

Do you require access to:

1. Quantitative MRI data? Yes [ ]  No [ ]

# Raw images to allow you to conduct your own MRI analyses? Yes [ ]  No [ ]

If Yes, please complete the electronic MSBIR data request form via the link below, hosted by the Sydney Neuroimaging Analysis Centre (SNAC). Once submitted, a copy of this form will be sent to the MSBase Operations team, SNAC and yourself as the data requestor.

<https://vp4mmbybc3.execute-api.ap-southeast-2.amazonaws.com/v1/>

# Authorship criteria for this study

It is recommended that applicants read the MSBase Policy and Procedures on Authorship and Publications before completing this section. Available at [www.msbase.org](http://www.msbase.org) – log in to access Registry – Resources pages. Data recipients must adhere to the authorship proposal as provided below and where journal limits apply, follow the MSBase Policy and Procedures on Authorship and Publications.

1. Minimum number/proportion of analyzable patient datasets required for authorship:

(*Note: this figure would usually be lower where the inclusion criteria are more restrictive. The minimum authorship threshold in the past has ranged from 5 to 20. Advice can be sought from the committee.)*

Click here to enter text.

1. Timeframe for responding to publication process/paperwork to primary author will be 2 weeks unless another timeframe is specified. In special circumstances and upon request from an author, the timeframe can be extended up to 4 weeks. The names of the investigators who do not respond within the defined timeframe will be moved from the list of authors to the list of contributors.

Click here to enter text.

1. Other criteria for authorship

Click here to enter text.

# Acknowledgement/Contributorship criteria:

1. Number of analysable patient datasets required for acknowledgement will be 1 unless otherwise specified

Click here to enter text.

1. Timeframe for responding to publication process/paperwork will be 2 weeks unless another timeframe is specified.

Click here to enter text.

**\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\***

If you also wish to apply for statistical support complete the

***FORM:*** [***MSBase access to scientific review and/or statistical support request***.](FORM_MSBase%20request%20to%20access%20statistical%20support_June%202022.docx)

If you have any queries about this process email info@msbase.org.

**Appendix 1
The MSBase Minimum Dataset and data required for “Complete Records”**

The table below indicates the minimum dataset recommended for clinicians participating in the MSBase Registry. Records are considered complete when the fields circled in red in the table below have been filled.

Fields that are **not** in red text, are all fields that are *recommended* to complete annually, for the purposes of capturing quality data.

 Complete Records fields

|  |  |  |  |
| --- | --- | --- | --- |
|  | Field | Frequency | Definition |
| Patient Profile | Patient ID | Entry Visit | Patient globally unique ID (system creates) |
|  | Sex | Entry Visit | M / F |
|  | Birth date | Entry Visit | Month and year only |
|  | Date of MS onset | Entry Visit | Date |
| Visits | Visit Date | Entry & Annual # | Date |
|  | KFS – 8 itemsEDSS\*  | Entry & Annual #Entry & Annual # | 0 to 5 / 0 to 6 / 0 to 120 to 10 |
| Paraclinical tests | Test date | Entry & Annual # | Date |
|  | Test type | Entry & Annual # | MRI, CSF, EP, Biochemistry |
| Relapses | Relapse Date | Entry & Annual # | Date |
|  | CNS region | Entry & Annual # | Pyramidal, Cerebellum, Brainstem, Sensory functions, Bowel bladder, Visual functions, Neuropsychological functions |
|  | Corticosteroids | Entry & Annual # | Yes, No |
| Treatments | Treatment ID | Entry & Annual # | Treatment names |
|  | Start date | Entry & Annual # | Date |
|  | End date | Entry & Annual # | Date |