

SWIMS DATA SHARING APPLICATION FORM

1. Read the SWIMS Data Sharing and Collaborative Research Policy (*copies available from the SWIMS website or on request from the SWIMS Team*)
2. Complete the application forms and return them to the SWIMS Team by post or email. Emails should carry the header "DATA SHARING REQUEST".
3. We will acknowledge your request and estimate a date by which we expect to have been able to review your request. Please remember though, that we are only a small team and staff are not always available at short notice.
4. If there are any obvious omissions on the form we will advise you before the review.
5. After the review we will either:
 - Contact you to advise we have accepted your request and to discuss how to proceed, or
 - Advise you of our reasons for turning down your request, or
 - Ask you to discuss possible amendments that might mean we can accept your request.
6. Once we have agreed a request we will agree the contents of the Data Sharing Agreement with the Applicant. This agreement and any necessary permits or approvals **MUST** be in place before any sharing of the Data can begin. We will also provide an estimate of how long we will take to supply the Data **but** we will not undertake any such work until all agreements are in place.
7. If you have any queries please contact the SWIMS Coordinator:

SWIMS PROJECT
N16, ITTC Building 1
Plymouth Science Park
Derriford
PL6 8BX

01752 315246

swimsproject@plymouth.ac.uk

<http://research.psmd.plymouth.ac.uk/cnrg/swims.php>

SWIMS DATA SHARING REQUEST FORM

**Applicant
(Full name)**

Click here to enter text.

Role

Click here to enter text.

Institution

Click here to enter text.

Contact details

Telephone: Click here to enter text.
Mobile: Click here to enter text.
Email: Click here to enter text.

Co-Applicants

Click here to enter text.

Project Title

Click here to enter text.

| Has the project been or will it be peer reviewed? | |
|---|--|
| YES <input type="checkbox"/> | If YES by which organisation and when? Click here to enter text. |
| NO <input type="checkbox"/> | If NO , why not? Click here to enter text. |
| How will the project be funded? Click here to enter text. | |
| Has funding been approved? | |
| YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| If no, date approval decision expected? (dd/mm/yyyy) | |
| <input type="text" value="Click here to enter a date."/> | |

DATA REQUESTED

| | |
|--|----------------------------------|
| <p>General description of Data requested</p> <p>(use form on page 3 to list exact data requested)</p> | <p>Click here to enter text.</p> |
| <p>Purpose of request / rationale for using SWIMS data</p> <p>(include aims, hypotheses, outcome variables, confounding variables etc.)</p> | <p>Click here to enter text.</p> |
| <p>Endpoint of proposed research</p> | <p>Click here to enter text.</p> |

Does the study have ethical approval from a recognised Institutional Review Board / Ethics Committee?

YES NO N/A

If YES, please attach a copy of the approval.
If NO or N/A please specify reasons/steps being undertaken to arrange for approvals:

Click here to enter text.

DATA REQUESTED

| General questions: | Tick if requested | Raw data or summary? e.g. total number of symptoms | Time points FROM TO | | Restrictions or exclusions? e.g. age 45 or over; PDDS < 6 |
|---|--------------------------|--|------------------------|-------|---|
| Date of first symptoms | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Date of first visit to GP | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Date diagnosed with MS | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Relapses* | | | | | |
| Number/Date/Duration of relapses | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Hospital admission/use of steroids | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Effect upon work/other activities | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Visits to specialists: contact with health and social care professionals | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Medications | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Current symptoms | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Investigations | | | | | |
| Brain scan/MRI/CT/Lumbar puncture/electrical tests | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Type of MS*** | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Worsening? does participant report deterioration in previous six months | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Assistance: Help needed to complete form? | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Change of diagnosis? | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| PROM DATA: | | | | | |
| EuroQol (EQ-5D) | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Fatigue Severity Scale (FSS) | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Functional Assessment of MS (modified 44-items scale) (FAMS) | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| General Health Questionnaire-30 (GHQ-30) | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Medical Outcomes Study Short Form 36 Item Health Study (SF-36v2) | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| MS Disease Impact Scale-29 (MSIS-29 v2) | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| MS Neuropsychological Screening Questionnaire (MSNQ) | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| MS Walking Scale (MSWS-12 v2) | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Patient Determined Disease Steps (PDDS) | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |
| Postal Barthel Index (PBI) | <input type="checkbox"/> | Click here to enter text. | mm/yy | mm/yy | Click here to enter text. |

DATA REQUESTED

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| Demographic Data Requested (if any) <i>e.g. age at diagnosis, sex</i> | |
| Click here to enter text. | |
| Click here to enter text. | |
| Click here to enter text. | |
| Click here to enter text. | |
| Click here to enter text. | |

| | |
|---|--|
| Analyses to be performed by proposed collaborator <i>(please continue on a new sheet if necessary)</i> | |
|---|--|

| Data to be used | Analyses |
|---------------------------|---------------------------|
| Click here to enter text. | Click here to enter text. |
| Click here to enter text. | Click here to enter text. |
| Click here to enter text. | Click here to enter text. |
| Click here to enter text. | Click here to enter text. |
| Click here to enter text. | Click here to enter text. |
| Click here to enter text. | Click here to enter text. |

DATA REQUESTED

| Further project specifications | |
|---|---|
| Date Data required (dd/mm/yyyy) | Click here to enter a date. |
| Desired format of data | Click here to enter text. |
| People to have access to the data: | |
| Name | Role/Reason for access |
| Click here to enter text. | Click here to enter text. |
| Click here to enter text. | Click here to enter text. |
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| Click here to enter text. | Click here to enter text. |
| Date storage and security / management procedures Please attach the following policies for your institution: (i) Data security policy (ii) Data destruction policy | Click here to enter text. |
| Contact details for queries about data export/format | <i>Name:</i> Click here to enter text. |
| | <i>Telephone:</i> Click here to enter text. |
| | <i>Email:</i> Click here to enter text. |
| ETHICAL AND RESEARCH APPROVALS NEEDED | |
| Approvals needed If already obtained please attach a copy, if none needed please explain why: | Click here to enter text. |
| Dates applications to be made (dd/mm/yyyy) | Click here to enter a date. |

DATA REQUESTED

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| Other approvals needed | Click here to enter text. |
| Dates applications to be made (dd/mm/yyyy) | Click here to enter a date. |

| | |
|--|-----------------------------|
| Date of request (dd/mm/yyyy) | Click here to enter a date. |
| Signature of applicant | Click here to enter text. |
| PRINT NAME | Click here to enter text. |

| | |
|--|-----------------------------|
| Date Received by SWIMS (dd/mm/yyyy) | Click here to enter a date. |
| Reference number | Click here to enter text. |