

## Data Access Summary

The BRAINS imagebank is collating anonymised images and associated clinical data from ‘normal’ individuals at all ages (from prenatal to old age) primarily in Scotland. These have been collected from participants in several healthy volunteer studies. BRAINS only includes information that the original study team have provided: additional data may have been collected (see [www.brainsimagebank.ac.uk](http://www.brainsimagebank.ac.uk) for full details of the primary studies). The BRAINS team based in the University of Edinburgh hosts the data, on behalf of, and under the governance of, a Scotland-wide steering committee which comprises: principal investigators of the original studies (including experts in obstetrics, paediatrics, geriatrics, neuroimaging, psychology); experts in ethics, governance and law, and two lay representatives or other relevant persons and/or bodies (the “**BRAINS Steering Committee**”). All applications for data use will be reviewed and approved (or not) by the BRAINS Steering Committee.

If you would like to request data from the BRAINS imagebank, this Agreement states that:

- You (the Principal Applicant) will make a written application that will be reviewed and approved (or not) by the BRAINS Steering Committee.
- You are responsible for the use of the data you receive. You should name on the data access form the principal applicant and all other team members (if applicable) who will access the data, and will not share the data with anyone else.
- If derived data are created (e.g. new variables, imaging templates etc) you should discuss with the BRAINS team returning the derived data to the BRAINS imagebank.
- Derived data remain the property of the BRAINS imagebank (University of Edinburgh) unless otherwise agreed.
- The data will not be used for purposes other than those in the application; a further application can be submitted if required.
- You will acknowledge BRAINS (see form of words at [www.brainsimagebank.ac.uk](http://www.brainsimagebank.ac.uk)) in any presentations or publications using the data.

If you would like to access the data in the BRAINS imagebank, please print out and complete the ‘Data Access Schedule’ form below, sign it, and email a pdf copy to the

BRAINS team at [brains@ed.ac.uk](mailto:brains@ed.ac.uk), or by post to BRAINS, CCBS, Chancellor's Building, 49 Little France Crescent, Edinburgh, Scotland, UK, EH16 4SB.

**DATA ACCESS SCHEDULE**  
***Access of Data from the BRAINS Image Bank***

**This Data Access Schedule and the Data Access Summary sets out the terms and conditions on which the Data will be accessible by the Applicant**

For the purpose of this Schedule, the following terms shall be understood to mean:

|                                    |  |
|------------------------------------|--|
| <b>"Agreement"</b>                 | This Schedule and the Data Contribution summary.   |
| <b>"Applicant(s)"</b>              | Any applicant whose application for access to the Data and/or the BRAINS Image Bank has been approved by the BRAINS Steering Committee.  |
| <b>"BRAINS Steering Committee"</b> | Means the BRAINS Steering Committee as defined in the Data Contribution Form Summary.  |
| <b>"Data"</b>                      | A range of data provided with consent by healthy volunteers in research studies including but not limited to demographic data (eg age, social class), clinical data (eg medical history, medication, blood pressure, cognitive tests) and brain imaging data.  |
| <b>"Data Contributor"</b>          | Means the applicable party that has contributed to the Data.   |
| <b>"Derived Data"</b>              | The data, datasets, algorithms and /or derived variables used therein which may be derived from the use or analysis of the Data by Applicants in carrying out the Project, including but not limited to the BRAINS Image Bank.   |
| <b>"Edinburgh"</b>                 | The University Court of The University of Edinburgh, a charitable body registered in Scotland under registration number SC005336, incorporated under the Universities (Scotland) Acts and having its main administrative offices at Old College, South Bridge Edinburgh, EH8 9YL.  |
| <b>"Term"</b>                      | Access will be provided for one year in the first instance and may be extended on application to the BRAINS Steering Committee. Any extended period will be notified by the BRAINS Steering Committee to the Applicant in writing.   |
| <b>"Project"</b>                   | The BRAINS Image Bank will be accessible via the internet (after application to and approval by the BRAINS Steering Committee) to allow Applicants to explore brain changes with different clinical features at different ages (such access shall be governed by the terms of a data use agreement to be agreed by the BRAINS Steering Committee). |

1. The Data have been provided to the BRAINS Team to enable Edinburgh to host the BRAINS Image Bank, on behalf of the BRAINS Steering Committee, which incorporates the Data provided by the Data Contributors (including Edinburgh).
2. The Applicant acknowledges and agrees that only the Applicant and those individuals named in the schedule attached to this agreement, or as agreed with Edinburgh in writing after application, working under the Applicant's direct supervision are permitted to have access to and to use the Data. The Data must be accessed and used solely for the purpose of carrying out the Project and shall not be accessed and used for any other purpose, other than with the prior written consent of the BRAINS Steering Committee. The Applicant shall ensure that the named individuals comply with the terms of this Agreement as though they were the Applicant and the Applicant shall be responsible for any breach of this Agreement by such named individuals.
3. The Applicant will use the Data in accordance with all applicable laws, regulations and research governance.
4. The Applicant undertakes to make no attempt to link the Data to other datasets held by different recipients or by the Applicant for different projects, without the prior written consent from the BRAINS Steering Committee, or to use the Data to identify the Data subjects.
5. The Data and all intellectual property rights therein will remain the property of Edinburgh (as custodian for the BRAINS Steering Committee) or the Data Contributor(s) as the case may be, at all times and no right, title or interest in or to the Data and/or the Derived Data is granted to the Applicant other than as expressly set out in this Agreement.

6. Edinburgh will own (as custodian for the BRAINS Steering Committee) all Derived Data and all intellectual property rights therein. The Applicant shall provide the Derived Data to the BRAINS imagebank once available. Edinburgh agrees to provide the Applicant with access to the Derived Data and hereby grants to the Applicant a non-exclusive, royalty-free licence to use the Derived Data for the purpose of the Project.
7. The Applicant will keep the Data and/or the Derived Data confidential for so long as such Data and/or Derived Data remain confidential in nature, notwithstanding termination or expiry of this Agreement, other than for the purposes of the Project. The obligation in this Clause 7 shall not apply where the Applicant can prove that the Data and/or Derived Data and/or Confidential Information:
  - (a) has become public knowledge, other than through an unauthorised disclosure by the Applicant;
  - (b) was already known to the Applicant prior to disclosure by the BRAINS Steering Committee and/or Edinburgh and was independently developed by the Applicant without use of or recourse to the Data and/or Derived Data;
  - (c) was disclosed to the Applicant by a third party not under any obligation of confidence to the Data Contributors and/or the BRAINS Steering Committee and/or Edinburgh; or
  - (d) is required to be disclosed by law or by requirement of a regulatory body or court order.
8. Any publications made by any Applicant and/or the BRAINS Steering Committee of results arising from any analysis of the Data and/or Derived Data will be produced in accordance with normal academic practice including (without limitation) appropriate acknowledgement of co-authors, any published paper from which the Data and/or Derived Data derives, the version of the Data and/or Derived Data used, the role of the Applicant and/or the BRAINS Steering Committee, the relevant primary collectors of the Data and/or Derived Data and their funders (including but not limited to SINAPSE and any funders listed on the BRAINS website [www.brainsimagebank.ac.uk](http://www.brainsimagebank.ac.uk)). Any publications should follow citation guidance as provided on [www.brainsimagebank.ac.uk](http://www.brainsimagebank.ac.uk), including reference to this website and the Protocol for the Project, unless the Applicant is notified otherwise.
9. The Applicant acknowledges and agrees that access to, and use of, the Data and/or Derived Data is provided by each of the BRAINS Steering Committee, the Data Contributors and Edinburgh on an "as is" basis. Each of the BRAINS Steering Committee, the Data Contributors and Edinburgh give no warranty, express or implied, that:-
  - (a) the Data and/or Derived Data are accurate or complete;
  - (b) the Data and/or Derived Data are fit for any particular purpose; or
  - (c) the Applicant's use of the Data and/or Derived Data will not infringe any third party intellectual property or other rights.
10. The Applicant accepts and agrees that it will access the Data and/or Derived Data during the Term only. The Applicant accepts and agrees that:
  - (a) the BRAINS Steering Committee and/or Edinburgh may terminate the Applicant's access to the Data and/or Derived Data forthwith upon any breach of this Agreement by the Applicant; and
  - (b) the BRAINS Steering Committee and/or Edinburgh may terminate the Applicant's access to the Data and/or Derived Data upon giving the Applicant fifteen days' written notice.
11. On termination or expiry of this Agreement, the Applicant shall immediately destroy or return (as determined by the BRAINS Steering Committee and/or Edinburgh) all tangible copies of the Data in its possession or under its control and (to the extent possible to do so) delete all copies of the Data from its computer systems and confirm in writing to the BRAINS Steering Committee that this has been done.
12. The Applicant acknowledges and agrees that the provisions of this Agreement will continue in full force and effect following expiry of the Term or termination of the Applicant's access to the Data and/or Derived Data pursuant to the terms of this Agreement.
13. The parties agree that no party shall be liable for any indirect or consequential damages incurred by any other party under or in connection with this Agreement howsoever caused.
14. Nothing in this Agreement excludes, restricts or otherwise limits either party's liability for any death or personal injury arising from its negligence or for any loss suffered by the other party as a result of its fraud.
15. The parties acknowledges and agrees that the provisions of this Agreement will continue in full force and effect following expiry of the Project.
16. The Applicant will indemnify and hold harmless each of the BRAINS Team, the BRAINS Steering Committee, Edinburgh, and the Data Contributors in respect of any losses and/or liabilities, claims and expenses actually suffered by each of them as a result of the negligent acts and omissions of the Applicant, those supervised by the Applicant and its employees, agents or subcontractors (if applicable) in relation to the Project and/or any breach of the terms of this Agreement by the Applicant, or any of the foregoing.
17. The parties agree that Scots law shall govern this Agreement and the Scottish courts shall have exclusive jurisdiction over any matter relating to it.

**The Applicant hereby accepts the foregoing terms and conditions of this Agreement:**

Signed: \_\_\_\_\_ Date: \_\_\_\_\_  
(Principal Applicant, i.e. the **individual** completing the form)

Name: \_\_\_\_\_ Title: \_\_\_\_\_

For and on behalf of the **Applicant**:

Signed: \_\_\_\_\_ Date: \_\_\_\_\_  
(Authorised signatory of the **INSTITUTION**  
e.g. the University)

Name: \_\_\_\_\_ Title: \_\_\_\_\_

**Edinburgh hereby accepts the foregoing terms and conditions of this Agreement:**

For and on behalf of **The University Court of the University of Edinburgh**:

Signed: \_\_\_\_\_ Date: \_\_\_\_\_

Name: \_\_\_\_\_ Title: \_\_\_\_\_

## BRAINS Imagebank Data request form

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|---|
| <b>Provisional title of study</b>   |
| <b>Principal applicant (include institution address, email &amp; phone)</b> |
| <b>Named researchers (in addition to principal researcher if known)</b>     |
| <b>Provisional author list</b>  |
| <b>Brief rationale for study</b>  |
| <b>Variables to be analysed</b>   |
| <b>Which journal(s) are you considering?</b>                                |

If approval granted

Signed: \_\_\_\_\_ Date: \_\_\_\_\_  
(on behalf of BRAINS steering committee)