|  |
| --- |
| Project number: yyyy/seq. no **(NBB use only)** |

**Application Form Data Mining**

*This form must be used for those who wish to request NBB donor data1 only. Applicants wishing to request donor data in addition to tissue for the same project must use the tissue application form.*

*The NBB processes personal data in line with its* ***privacy notice*** *which can be found on* [*the NBB webpages*](https://www.brainbank.nl/privacy-statement/)

1. **Applicant details**

|  |  |
| --- | --- |
| Date of application |  |

1. **Main applicant details**

|  |  |
| --- | --- |
| Name Applicant |  |
| Institute |  |
| Department |  |
| Street + number |  |
| Postal code and city |  |
| Country |  |
| Phone |  |
| Email address |  |
| [ORCID](https://orcid.org/) of PI |  |

1. **Principal investigator details if different from applicant**

|  |  |
| --- | --- |
| Name Applicant |  |
| Institute |  |
| Department |  |
| Street + number |  |
| Postal code and city |  |
| Country |  |
| Phone |  |
| Email address |  |
| [ORCID](https://orcid.org/) of PI |  |

1. **Internal/external co-investigators, collaborators and other parties**
   1. Are data being requested from other Banks or collections? What data will each bank provide?
   2. Do you intend to share the data you will receive from the NBB with persons outside the organisation mentioned in A1 and A2? You can either state this now or submit a written request at a later stage. You will need to specify the organisation and the role they have in this project.
2. **Project details**
3. **Title of the research project**
4. **Dates**

|  |  |
| --- | --- |
| Start date |  |
| End data of data analysis |  |

1. **Background**
   1. Background and references to own and other relevant work in this line of research
   2. Rationale, hypothesis and aim
   3. Brief method (what kind of output data 1 do you expect to and how will you use this to answer your research question)
2. **Summaries**

As part of the NBB’s commitment to transparancy for donors, the research community, regulators, funders and the public the NBB reports and publishes information on the projects that are submitted to it and the decisions it takes. To this end, the NBB asks each applicant to provide two project summaries that are linked to applicant name and affiliation.

1. **Scientific summary of the project for public NBB website and internal/external reporting** (max 250 words)

I wish to apply an embargo: due to commercial confidentiality, please do not publish this summary outside the NBB until:

I allow the NBB to publish my contact details along with my summary

1. **Lay summary of the project for public NBB website and internal/external reporting** (max 250words; please note, if written in English, the NBB may translate this to Dutch.)

I wish to apply an embargo: due to commercial confidentiality, please do not publish this summary outside the NBB until:

I allow the NBB to publish my contact details along with my summary

1. **Information on requested donor data/casess****[[1]](#footnote-1)**

*Please be as specific about the data as possible; keep in mind the search result in medical files will be context dependent*

1. Which key words need to be used for the data search; please specify
   * 1. which donor parameters (e.g. clinical diagnosis, symptoms, medication,neuropathology you are interested in?
     2. whether the search needs to match the exact words or parts of the word only
     3. search terms need to combined in ‘AND’ or ‘OR’ or ‘EXCLUDE’ manner
2. Do you want to receive all data that match the search criteria or do you have a pre-defined sample size (if so, please provide rationale)?
3. **Dissemination strategy**
4. Will data be entered into a database?
5. What kind of data are these (raw NBB donor data or extracted data)? Will data be combined with other clinical, neuropathological or tissue data?
   * 1. Is this database open access or not? You must not make original NBB data freely accessible; please contact the NBB if you have questions about this
6. **Further comments**
7. **Tick all key words that describe the project topic (this is used to categorise projects that use NBB data; not to search for cases/data)**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Neurodegenerative disorders:** | **Neuroinflammatory disorders:** | **Psychiatric disorders:** | **Other:** | **Controls (if controls are the donors of primary interest; not if researched matched with diseased)**: |
| Alzheimer’s disease | Multiple Sclerosis | Major depression | Epilepsy | Non-demented controls |
| Frontotemporal dementia | Other, please specify: | Schizophrenia | Narcolepsy | Other, please specify: |
| Parkinson’s disease/Dementia with Lewy Bodies |  | Bipolar disorder | Migraine |  |
| Multi-system atrophy |  | Obsessive-compulsive disorder | Cluster Headache |  |
| Progressive supranuclear palsy |  | Post-traumatic stress disorder | Cerebral infarction / hemmorrhage |  |
| Vascular dementia |  | Autism spectrum disorder | Other, please specify: |  |
| Motor Neuron Disease |  | Attention-deficit hyperactivity disorders |  |  |
| Other dementia, please specify: |  | Other, please specify: |  |  |
| Other, please specify: |  |  |  |  |

1. **Requirements for data recipients**

The NBB only supplies data (Material) that has been obtained on the basis of informed consent of the brain donor. Informed consent restricts the use of the Material to scientific

research purposes only. The Material shall only be supplied under the conditions stated in a Material Transfer Agreement (MTA), that needs to be signed by the person who is granted the power of representation within your organization. The MTA states the rights and obligations of the Provider as wel as the Recipient with regard to the Material and its use.

1. **Declaration**

I confirm that the information provided in this form is correct. I will abide by any provisions in the MTA that will be drawn up following approval and that I will hold any data sent to me in a secure location with access for the research team only.

|  |  |
| --- | --- |
| Name |  |
| Signature |  |
| Date |  |

**Contact information**

In case you need further information or have questions concerning the application form or availability of tissue, please don’t hesitate to contact us or look at our website ([www.brainbank.nl](http://www.brainbank.nl)). Please return the completed application form to [eNBB@nin.knaw.nl](mailto:eNBB@nin.knaw.nl).

1. With ‘Donor data’ the NBB means

   medical summaries (general information (demographics, drugs, education), family history, clinical diagnoses, symptoms/clinical parameters, medication, questionnaires and scores and pathological findings)

   or extracts from the database (for example post mortem delay or CSF pH) [↑](#footnote-ref-1)