

## **Draft Document**

### **Policy on Tissue Disposal for Brain Banks**

Tissue disposal is an integral component of brain banking and needs to be undertaken to ensure that there is efficient and effective use of storage space within the brain bank, particularly for frozen tissues. It is also essential to ensure that the cases stored in the brain bank are those of highest value to researchers and of highest tissue quality.

Tissue and data disposal is also required in order to be able to respond to changes in consent/authorisation status, particularly withdrawal of consent/authorisation.

Brain Banks differ in their physical capacity and location, and in the focus of their brain donation and tissue collection schemes. This policy is designed to accommodate these differences and to ensure that the principle of storage of high quality tissue samples and accompanying data in the brain banks is followed regardless of physical location.

Retention or disposal of tissues and data should be prioritised according to the following criteria:

#### **1. Priority for retention**

- a) Cases from well-characterised clinical cohorts with accompanying clinical data, including imaging, biomarker and genetic data.
- b) Rare disorders and genetic disorders that are infrequently encountered.
- c) Early onset neurodegenerative disorders with accompanying clinical data.
- d) Early disease stages, including early stage Alzheimer and Lewy body pathology, with accompanying clinical data
- e) Neuropsychiatric disorders with well documented clinical, drug and lifestyle histories.
- f) Cases with good clinical data and well characterised, good quality tissue: short post mortem interval, high brain pH, high RIN value, favourable agonal state.

#### **2. Priority for disposal**

- a) Cases with fixed tissue only of relatively poor quality: prolonged formalin fixation.
- b) Lack of adequate clinical data from hospital and GP sources.
- c) No frozen tissue available.
- d) Poor quality frozen tissue: prolonged post mortem interval, low brain pH, low RIN values, unfavourable agonal state .
- e) Lack of data on post mortem interval, brain pH and agonal state.
- f) Common conditions: cases of typical late-stage neurodegenerative diseases that have been stored for a prolonged period, but are regularly received as donations.

Cases for disposal should be assessed on an individual basis, using the criteria above as guidance. When disposing of poor-quality frozen tissue and cases with prolonged formalin fixation, it may be possible to retain the paraffin-embedded tissue blocks if these are of high quality and with a short fixation period, and if storage space permits.

Bearing in mind that each brain bank has its own particular disease focus, disposal should only take place after consideration of offering the case to another bank if it fits with their disease focus, eg CJD or HIV cases for the Edinburgh Bank, Lewy body dementia cases for the Newcastle Bank.

Disposal of tissue samples should be accompanied by disposal of relevant data with a clear record of when the tissue and data were disposed of.

When disposal occurs as a consequence of withdrawal of consent/authorisation, a record of the date of receipt of the instruction of change of consent/authorisation status, and the date of tissue and data disposal should be recorded. Disposal should be confirmed with the individual who has withdrawn consent in order that all parties may be satisfied that the wishes of the individual concerned have been complied with.

The physical disposal of tissues should comply with MRC, HTA and local NHS policies (see MRC Regulatory Support Centre Policies on Research and the Human Tissue Act 2004 – Disposal). The disposal of data should comply with MRC and local policies on research data.

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