

## **Brain and spinal cord retrieval for research**

### **A report by the HTA, July 2016**

#### **Background**

The HTA regulates establishments in England, Wales and Northern Ireland that store bodies prior to post-mortem (PM) examination, conduct PM examinations and remove tissue samples (relevant material) from the deceased, for example for use in research.

Removal of tissue from the deceased must take place on premises licensed for this activity by the HTA. The HTA licenses around 175 establishments for the removal of tissue. These include public mortuaries managed by Councils and hospital mortuaries within NHS Trusts.

Concerns were raised with the HTA that brain banks may be experiencing increased difficulties in retrieving brain tissue for use in research, particularly when death occurs at the weekend. This has resulted in one of the major brain banks closing down its 24-hour help line for families of donors.

There is little indication that HTA licensing is a barrier to tissue retrieval, and promotion of tissue retrieval is not a function of the HTA. However, the HTA is in a good position to gather information and provide advice to those involved, which may help facilitate brain donation and avoid unnecessary distress to families anxious to fulfil the wishes of their deceased relative. As a result, in September 2015, the HTA invited all establishments licensed in the PM sector to participate in a survey on tissue retrieval practices at their premises (see Appendix 1).

In doing this, our aims were:

- to evaluate the level of tissue retrieval activity undertaken by establishments;
- to identify what, if any, are the barriers to tissue retrieval; and
- to determine what, if anything, might be done to remove these barriers.

#### **Tissue retrieval activity: survey findings**

We had responses from 49 establishments. Of these:

- 38 stated that they undertake retrieval of brain and/or spinal cord for use in research,

- 11 establishments stated that they do not.
- There was some variation in the response rate across England, Wales and Northern Ireland:
  - Yorkshire & Humberside had the highest percentage of mortuaries which carry out brain and spine removal.
  - This was closely followed by the South of England (both East and West).
  - London and East of England had the lowest percentage.
- 29 establishments stated that they would be willing to be included on a list of establishments able to undertake retrieval of brains and/or spinal cords - their details will be provided to brain banks and available via the HTA website here - <https://www.hta.gov.uk/regulated-sectors/post-mortem>.
- 21 of the respondents undertaking retrievals stated that they do not perform this activity out of working hours:
  - The main barrier cited by these establishments was obtaining the medical certificate of cause of death in a timely manner.
  - Only three establishments cited staff availability or lack of payment as a barrier to retrieval.
  - Getting agreement from the coroner and incorrectly completed consent forms were also cited as concerns.
- Brain and spinal cord retrieval is undertaken by Anatomical Pathology Technologists (APTs) only at 29 of the responding establishments:
  - Two establishments indicated that retrievals are undertaken by Pathologists only.
  - Four establishments stated retrievals are performed by Pathologists and APTs.
  - There was great variation in the number of APTs trained to undertake brain and/or spinal cord retrieval at establishments.
- Of the 38 respondents who undertake brain and/or spinal cord retrieval:
  - 15 undertake one to four retrievals each year and ten establishments undertake five to nine retrievals.

- Five undertake ten to 19 a year.
  - Three establishments undertake 20 or more retrievals each year.
- Information from 26 respondents indicated that they have capacity to increase the number of retrievals they undertake each year.

## **Potential barriers to tissue retrieval**

Only nine establishments stated that they do not experience any barriers to brain retrieval. Given that 26 indicated that they have capacity to increase the number of retrievals, it is important to understand and address problems that are preventing them from doing so.

- Some brain banks have suggested that there is a correlation between the number of mortuaries willing to perform brain and spinal cord retrievals and the number of retrievals undertaken each year. However, the findings of the survey indicate that establishments who are willing and able to undertake retrievals have the capacity to increase the number.
- Notably, eight of the 11 establishments who reported that they do not currently undertake brain and/or spinal cord retrieval stated that they have not been asked to.
  - Three of these establishments have agreed to be included on the list of establishments to be provided to brain banks.

We asked establishments to tell us the barriers to tissue retrieval that they experience. A number of common themes emerged

### ***Workload and staff availability***

- Eleven establishments stated that workload and staff availability limit the number of retrievals that they are able to perform each year.
  - Some establishments commented that workload pressures are greater during winter periods, when death rates are higher and mortuary workload increases.
- Establishments were asked whether they would be willing to allow fully trained tissue bank staff to attend their mortuary to retrieve tissues.
  - 25 establishments that responded to the survey stated that they would allow access to tissue bank staff for this purpose.

- However, establishments frequently commented that even if a team of external staff were to attend the mortuary to undertake the retrieval process, workload pressures may still limit the number of retrievals that could take place due to availability of mortuary facilities.
- Additionally, some establishments expressed concerns about oversight of external staff and that training would be necessary in local procedures. In particular, concerns about the rigour of identity checks were raised and the necessity for a member of mortuary staff to be present to confirm the identity of the deceased.

### ***Delays in arrangements for tissue retrieval***

- Brain banks require brain and spinal cord retrieval to be undertaken within a 48 – 72 hours of death. This imposes significant time pressures for all parties involved to ensure the retrieval can take place within this timeframe.
- Six establishments cited delays in receiving the necessary paperwork confirming that consent has been given for tissue retrieval as a barrier to retrieval.
- Three establishments stated that they have experienced delays in receipt of the Medical Certificate of the Cause of Death (MCCD), necessary for the retrieval to proceed.
- Where a death may be referred to the Coroner for investigation, agreement from the Coroner is required before brain and/or spinal cord retrieval can proceed and the pathologist should examine the body before the retrieval commences.
  - Two establishments cited delays in communication with the Coroner as a barrier to tissue retrieval.
- Four establishments cited delays in the transfer of bodies to the mortuary as a barrier to tissue retrieval, as these can reduce the time available to mortuary staff to undertake the retrieval.
- Staff training does not appear to be a significant barrier brain retrieval, with only two establishments citing staff competence as a barrier to retrieval at their establishment.
  - However, 23 establishments stated that they would find it useful for staff at their establishment to attend a workshop on brain and spinal cord retrieval processes.
- Given that the majority of establishments indicated that tissue retrieval is undertaken only by APTs, initiatives aimed at supporting training in brain and spinal cord retrieval may be focused primarily at APTs.

- This was reinforced by 28 establishments stating that there is a need for APT training on spinal cord removal, which is a more complex procedure, undertaken infrequently.

### ***Payment for undertaking retrievals***

- Only one establishment cited the lack of payment for performing retrievals as a barrier to the number of retrievals performed at their establishment.
- Although payment for tissue retrieval does not appear to be significant barrier, more clarity is needed on the arrangements for payment for retrievals and costs incurred in transporting the body to the mortuary for retrieval to take place.

### ***HTA licensing arrangements***

- Only two establishments are not licensed by the HTA to undertake tissue retrieval for use in research on their premises.
- One of these does not undertake PM examinations and does not wish to extend the scope of their licence to include removal of tissue from the deceased.
- The other establishment is licensed for removal of relevant material and so could lawfully undertake tissue retrieval for use in research. We have contacted this establishment to provide clarification on the activities for which they are licensed.
- There is no evidence that HTA licensing is a barrier to tissue retrieval for research. However, we will provide additional information about HTA licensing requirements in the guidance provided to establishments on our website.

### **Summary of survey of HTA licensed establishments**

- The responses to our survey of HTA-licensed establishments suggest that the key barriers to brain and spinal cord retrieval are:
  - the workload and availability of staff at establishments;
  - delays in arrangements for tissue retrieval, including in the provision of consent documentation and the MCCD; and
  - a failure by brain banks to approach mortuaries about retrieval.
- Staff availability, payment for retrievals and HTA-licensing arrangements do not appear to restrict tissue retrieval at these establishments.

- Further information and clarification on brain and spinal cord retrieval processes may help to remove perceived barriers to tissue retrieval.
- Provision of training for mortuary staff would be welcomed by a number of establishments.

## **Association of Anatomical Pathology Technologists**

- Discussions with representatives from the Association of Anatomical Technologists (AAPT) identified some practical problems, which were not raised by survey respondents:
  - The lack of freezing facilities needed for storage of brains prior to collection by brain bank staff for brain banks that do not arrange immediate collection;
  - The lack of availability of bodies on which APTs can practise retrieval, especially retrieval of the spinal cord which is not a routine procedure during a post-mortem examination;
  - The need to cover the costs for on-call availability of APTs to perform retrievals out of hours.

## **Brain bank website audit**

The HTA reviewed the information available on brain bank websites; this was particularly in relation to the information that is available for families and what they need to do immediately after the death of a donor.

- The HTA is aware that donors are given information when they register with a brain bank to become a donor, but this information may not be readily available to next of kin when they need it. We considered what information would be available to a family were they to access the internet for information about what to do following the death of their relative.
- Many of the internet searches on brain donation led to the HTA website.
  - There are 12 brain banks listed on the HTA website; of those, only two have a website address listed on their address details.
- Upon a further Google search for the other brain banks, ten came up when their name was entered; however, two of the brain banks could not be found at all.
- A review of those brain bank sites that could be found on Google identified five that did not have any information for next of kin. Of those that did have information:

- Only one had the information in a clearly labelled section on the website.
- In most cases the information is included in a FAQ section with information for prospective donors.

### **Advice for Brain Banks following the audit**

- In order to facilitate the speedy retrieval of brains and to help families fulfil the wishes of the donor, brain banks are advised to review the information available on their websites for families. Access to helpful and instructive information in the critical period after death is extremely important, particularly in the absence of a 24-hour helpline.
- Brain banks should ensure there is a link to the relevant page on their website included with their details on the HTA website. It may be useful to have different links to the sections containing information for those considering donation and for their next of kin.
- Brain banks that have information for families mixed in with FAQs or other information for donors and prospective donors should separate the information, ensuring that it is clearly sign posted.
- Brain banks should consider including information on additional steps that the deceased's family could take to expedite the process, such as informing the certifying doctor of the urgency of the request or preparing the funeral director for the transfer of the body to the mortuary.
- If any of the brain banks listed on the HTA website would like feedback from the HTA about their website, they should contact [Emer.O'Toole@hta.gov.uk](mailto:Emer.O'Toole@hta.gov.uk).

## Summary table of recommendations/actions

Recommendation/Action	HTA	AAPT	Brain Banks	MS Society
Provide to brain banks the list of mortuaries able to perform brain retrievals	√			
Increase opportunities for AAPTs to develop their experience of spinal cord removal, including practical training and learning resources (such as a training video)		√	√	√
Increase GPs awareness of the need to complete the MCCD form as soon as possible where brain donation is indicated – guidance note for GPs to be drafted for and distributed by the Family Doctors Association	√			
Through the HTA's Histopathology Working Group, consult with the Coroners Society of E&W and RCPATH about how to prevent delays that might occur during the Coroners autopsy process	√			
Improve information for donors and their families on brain bank websites			√	√
Improve brain bank procedures to collect a brain promptly following retrieval			√	√
Increase awareness of HTA licensed mortuaries that removal for research is permitted under a PM Sector licence	√			

## Appendix 1: Brain and spinal cord retrieval survey

1. Do you undertake retrieval of brains/spinal cords for use in research?
  - a. Yes
  - b. No
2. If you do not undertake retrieval of brains and/or spinal cords for use in research, can you tell us why?
3. Which staff undertake the retrieval process at your establishment?
4. How many staff at your establishment are trained to undertake retrieval of brains/spinal cords?
  - a. None
  - b. 1
  - c. 2
  - d. 3
  - e. 4
  - f. 5 or more
5. Approximately how many retrievals do you undertake each year?
  - a. None
  - b. 1-4
  - c. 5-9
  - d. 10-19
  - e. 20 or more
6. Where are the tissues sent? Please indicate which tissue banks you work with.
7. Do you undertake tissue retrieval out of hours?
8. How many retrievals for brain banks would you be able to accommodate on an annual basis?
  - a. None
  - b. 1-4
  - c. 5-9
  - d. 10-19
  - e. 20 or more
9. What are the current barriers to retrieval of brains and/or spinal cords for use in research?
10. Would you be willing to allow fully trained tissue bank staff to come and retrieve tissue themselves at your facility? If no or don't know, please provide a reason for your answer.
11. Do you think there is a need for APT training on the process for retrieving brains and spinal cords?
12. Would you find it useful to attend a workshop on the brain and spinal cord retrieval process?

13. Is there any information that you would find useful to be included in our [FAQs on brain and spinal cord donation](#)?
14. Would you be happy to be included on a list of establishments willing to undertake tissue retrievals, to be provided to brain banks?