ANNEX J

Assessment to be carried out before surgery and endoscopy to identify patients with, or at risk of, CJD and vCJD

Summary of advice (revised 1 May 2008)

Annex J has been updated to provide a clear and pragmatic assessment of CJD and vCJD risk prior to surgery or endoscopy.

There are growing numbers of patients who have been informed that they are at increased risk of CJD or vCJD. Thus it is now recommended that all patients about to undergo any surgery or endoscopy should be asked if they have ever been notified as at risk of CJD or vCJD for public health purposes. This recommendation is outlined in paragraphs J1 and J2.

In addition, those patients about to undergo surgery or endoscopy which may involve contact with tissues of potentially high level TSE infectivity ("high risk tissues") should be assessed for CJD/vCJD risk through a set of detailed questions relating to possible exposure to CJD/vCJD. These questions are outlined in Table J1 and paragraphs J3 to J6.

New information has also been added in three key areas:

- Treatment with human pituitary-derived gonadotrophin – the use of human pituitary-derived gonadotrophin treatment was discontinued in the UK in 1973, but may have continued in other countries after that time
- Emergency surgery or endoscopy involving contact with high risk tissues – if the patient, a family member, or someone close to the patient is unable to answer the CJD/vCJD risk questions as outlined in Table J1 then the patient's general practitioner (GP) should be contacted for information concerning the patient's CJD risk following the surgery or endoscopy. All instruments used during the surgery or endoscopy should be quarantined until the information is obtained
- What to do if a patient is identified as potentially at risk of CJD/vCJD – paragraph J6 outlines the actions that should be taken if a patient is identified as at risk of CJD/vCJD following the questions in Table J1

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Recommendation for all surgical and endoscopy patients

J1. At a local level a policy should be put in place to ensure that patients who have been notified they are at increased risk of CJD/vCJD are identified before surgery or endoscopy, thus allowing the appropriate infection control procedures to be followed.

All patients about to undergo **any** elective or emergency surgical or endoscopic procedure should be asked the question:

"Have you ever been notified that you are at risk of CJD or vCJD for public health purposes?"

The CJD Incidents Panel has identified a number of individuals who are at risk of CJD or vCJD for public health purposes (see paragraphs J14 – J18).

J2. The actions to be taken following the patient's response to the above question are:

Patient's response	Action
No	Surgery or endoscopy can proceed using normal infection control procedures unless the procedure is likely to lead to contact with high risk tissue.
Yes	Please ask them to explain further. Special infection control precautions should be taken and the local infection control team should be consulted for advice. Part 4 of this Guidance provides advice for the precautions to be taken during the treatment of patients with or at risk of CJD and vCJD, and Annex F provides information on endoscopic procedures.
Unable to respond	Surgery or endoscopy can proceed using normal infection control procedures **unless** the procedure is likely to lead to contact with high risk tissue. If this is the case, please refer to the additional recommendations for high risk procedures from paragraph J3 onwards, with particular reference to paragraphs J7 – J10.

The patient's response should be recorded in their medical notes for future reference.

Additional recommendations for surgery and endoscopy which may involve contact with high risk tissue

N.B. These recommendations are applicable in particular to those assessing patients in neurosurgical and ophthalmic surgical departments

J3. As well as asking all patients whether they have been notified as being at risk of CJD/vCJD for public health purposes, clinicians assessing patients who are coming in for procedures that will involve contact with high risk tissues should ask supplementary questions (as outlined in Table J1) to further assess CJD risk.

J4. Tissues assumed or proven to have high level infectivity for CJD and vCJD are:

- Brain
- Spinal cord
- *Dura mater*
- Cranial nerves, specifically:
  - the entire optic nerve
  - only the intracranial components of the other cranial nerves
- Cranial nerve ganglia
- Posterior eye
- Pituitary gland

Annex A1 gives further advice on CJD/vCJD tissue infectivity

J5. Table J1 outlines recommended questions to further assess CJD risk. It is recommended that patients are asked these questions prior to elective or emergency surgical or endoscopic procedures likely to involve contact with tissues of potentially high infectivity. Paragraph J6 outlines the action to take based on the patient's responses.

Table J1 – CJD risk questions for patients about to undergo elective or emergency surgical or endoscopic procedures likely to involve contact with tissues of potentially high level infectivity

	Question to Patient	Notes to clinician
1	Have you any history of CJD or other prion disease in your family? If yes, please specify.	Patient should be considered to be at risk from familial forms of CJD linked to genetic mutations if they have or have had: i) Genetic testing, which has indicated that they are at significant risk of developing CJD or other prion disease; ii) A blood relative known to have a genetic mutation indicative of familial CJD; iii) 2 or more blood relatives affected by CJD or other prion disease
2	Have you ever received growth hormone or gonadotrophin treatment? If yes, please specify: i) whether the hormone was derived from human pituitary glands ii) the year of treatment iii) whether the treatment was received in the UK or in another country	Recipients of hormone derived from human pituitary glands, e.g. growth hormone or gonadotrophin, have been identified as at risk of CJD. In the UK, the use of human-derived growth hormone was discontinued in 1985 but human-derived products may have continued to be used in other countries. In the UK, the use of human-derived gonadotrophin was discontinued in 1973 but may have continued in other countries after this time.
3	Have you had surgery on your brain or spinal cord at any time in the past?	(a) People who underwent neurosurgical procedures or operations for a tumour or cyst of the spine **before August 1992** may have received a graft of *dura mater* and should be treated as at risk, unless evidence can be provided that *dura mater* was not used. (b) NICE guidance emphasises the need for a separate pool of new neuroendoscopes and reusable surgical instruments for high risk procedures on children born since 1st January 1997 and **who have not previously undergone high risk procedures.** These instruments and neuroendoscopes should not be used for patients born before 1st January 1997 or those who underwent high risk procedures using reusable instruments before the implementation of this guidance.

J6. The actions to be taken following the patient's response to the above questions are:

Patient's response	Action
No to **all** questions	Surgery or endoscopy can proceed using normal infection control procedures.
Yes to **any** of the questions	Further investigation into the nature of the patient's CJD risk should be undertaken by medical staff. The patient's CJD risk should be confirmed or rejected. Confirmation or rejection of CJD risk should be recorded in the patient's medical notes for future reference. If the patient is found to be at risk of CJD or vCJD following investigation, or the risk status is unknown at the time of the procedure, special infection control precautions should be taken, and the local infection control team should be consulted for advice. Part 4 of this guidance provides advice for the precautions to be taken during the treatment of patients with or at risk of CJD and vCJD, and Annex F provides information on endoscopic procedures. If the patient is found to be at risk of CJD or vCJD they should be referred to their GP, who will need to inform them that they are at risk of CJD or vCJD and provide them with further information and advice. This is available from the CJD Incidents Panel: http://www.hpa.org.uk/infections/topics_az/cjd/information_documents.htm
Unable to respond	See paragraphs J7 – J10 for advice.

The patient's response should be recorded in their medical notes for future reference.

Emergency surgery or endoscopy which may involve contact with high risk tissue

J7. In the event that a patient about to undergo emergency surgery or endoscopy is physically or otherwise unable to answer any questions, a family member or someone close to the patient (in the case of a child, a person with parental responsibility) should be asked the CJD risk questions as set out in Table J1 prior to the surgery or endoscopy.

J8. If the family member or someone close to the patient is not able to provide a definitive answer to the CJD risk questions, the surgery or endoscopy should proceed but all instruments should be quarantined following the procedure.

J9. The patient's GP should be contacted after the surgery or endoscopy, and enquiries made as to whether the patient is at risk of CJD/vCJD according to the CJD risk questions as set out in Table J1.

J10. The actions to be taken following the GP's response to the questions in Table J1 are:

GP's response	Action
No to **all** questions	The instruments can be returned to routine use after undergoing normal decontamination processes.
Yes to **any** of the questions	Further investigation into the nature of the patient's CJD risk should be undertaken by medical staff, and the patient's CJD risk confirmed or rejected. Confirmation or rejection of CJD risk should be recorded in the patient's medical notes for future reference. If the patient is found to be at risk of CJD or vCJD following investigation then the quarantined instruments should be destroyed. Alternatively, instruments destined for disposal may instead be retained for research – refer to Annex E for details. The patient's GP should inform the patient that they are at risk of CJD or vCJD and provide them with further information and advice. This is available from the CJD Incidents Panel: http://www.hpa.org.uk/infections/topics_az/cjd/information_documents.htm
Uncertain about **any** of the questions	The instruments should be kept in quarantine. The local infection control team should carry out a risk assessment, and they may wish to involve the local Control of Communicable Disease Consultant in this process. The outcome of the risk assessment should determine whether or not to return the instruments to routine use.

Additional actions to be taken during pre-surgery assessment for CJD risk

J11. In addition to asking the patient CJD/vCJD risk questions, the following actions should also be carried out before any surgical or endoscopic procedure involving contact with high risk tissue. The clinician undertaking the pre-surgery assessment should:

- Check the patient's medical notes and/ or referral letter for any mention of CJD/vCJD status
- Consider whether there is a risk that the patient may be showing the early signs of CJD or vCJD, i.e. consider whether the patient may have an undiagnosed neurological disease involving cognitive impairment or ataxia

J12. These actions, in conjunction with the CJD risk questions, will minimise the chance of a CJD incident occurring and therefore greatly reduce the risk of transmission of CJD/vCJD to subsequent patients.

Infection control guidance

J13. There are special infection control precautions that should be taken in healthcare for patients with, or at risk of, CJD/vCJD and Part 4 of this Guidance provides advice on these. Annex F provides information on endoscopic procedures.

Patients at risk of CJD or vCJD for public health purposes

J14. As outlined in Table 4A in Part 4, a number of patients have been identified as at risk for public health purposes on the recommendations of the CJD Incidents Panel. Paragraphs J15 to J17 provide some further information on these individuals and the steps taken to ensure that medical staff are informed of their risk status.

J15. This group of patients includes individuals identified to be at risk of:

- CJD/vCJD due to exposure to certain instruments used on a patient who went on to develop CJD/vCJD, or was at risk of CJD/vCJD;
- CJD/vCJD due to receipt of tissues/ organs from a donor later identified as at risk of or suffering from CJD/vCJD;
- vCJD due to receipt of blood components or plasma derivatives from donor(s) later identified as at risk of or suffering from vCJD;
- vCJD due to the probability they could have been the source of infection for a patient transfused with their blood who was later found to have vCJD

J16. When someone is notified that they are at risk of CJD or vCJD, they are asked to take certain precautions to reduce the risk of spreading the infection to others. These include:

- Not donating blood, tissue or organs;
- Informing medical and dental carers if they need to undergo an invasive procedure;
- Informing a family member or someone close to them, in case they need emergency surgery or endoscopy in the future

J17. The individual's GP is asked to record the patient's CJD risk status in their primary care records. The GP should also include this information in any referral letter should the patient require invasive medical procedures.

J18. Further information on the work of the CJD Incidents Panel is available on the HPA website: http://www.hpa.org.uk/infections/topics_az/cjd/menu.htm

Training

J19. Trusts should ensure that the healthcare workers conducting the pre-surgery assessment receive the instruction and/or training necessary to understand the underlying reasons for asking these questions. **It is crucial that these questions are asked in a manner that does not cause undue anxiety, and therefore the questioner should be prepared and able to reassure the patient, and provide further information if needed.**