

## WHAT TO DO IF YOU GET A PHONE CALL ABOUT A POTENTIAL CJD PATIENT

### PRE-ASSESSMENT

All patients should be asked the single question either at pre-assessment, on admission or at consent.

The single question is: **“Have you ever been notified that you are at increased risk of CJD or vCJD for public health purposes”**

You may get phone calls from pre-assessment when a patient has answered yes to the question

- 1) If the patient is a definite YES answer, if possible find out the reason why the patient has been notified as this can determine further actions
- 2) If the patient has not been able to give a reason why they have answered yes check with the nursing staff that the patient has understood the question (this is not as stupid as it sounds – there was a situation where the patient answered yes but no other evidence could support her answer, the nursing staff went back and asked again with more explanation and it turned out the patient thought they were asking about DVT when she was being asked about CJD)
- 3) Double check on Trakcare to see if they have a CJD alert – all Haemophiliac patients in NHSGGC were notified as “being at risk from CJD” for public health purposes and should have an alert on Trakcare, There may be other patients who will not have an alert on Trakcare e.g. patients who have received Growth Hormone.
- 4) If they don't have an alert the GP's should be contacted by the medical staff to ask if they know whether the patient has ever been told they are “at risk”
- 5) This is where it becomes complicated - if the patient is at risk from **Sporadic CJD/Familial CJD** the risk for surgery is low and instruments can be used and sent for re-processing at Cowlairs.
- 6) If they are at risk from **Variant CJD** then the risk for surgery is medium and instruments have to be quarantined see Annex M

<https://www.gov.uk/government/publications/guidance-from-the-acdp-tse-risk-management-subgroup-formerly-tse-working-group>

### IN-PATIENT

This may happen if the patient requires emergency surgery and cannot answer the single question and has no family who can be asked at the time and more likely to occur when high risk surgery is anticipated e.g. neurosurgery or ophthalmology

- 1) If it is emergency surgery then it should go ahead and any re-usable instruments should be wiped down and then quarantined until the status of the patient is determined.

- 2) Check on Trakcare to see if they have an alert re CJD – all patients in NHSGGC notified as “being at risk from CJD” for public health purposes will have an alert on Trakcare.
- 3) Get nursing staff to ask the family as soon as possible – a don’t know answer will be taken as a no answer
- 4) If they don’t have an alert or family to ask, the GP’s should be contacted if possible to ask if they know whether the patient has ever been told they are “at risk” – this should be done by the medical staff looking after the patient

Once an answer has been obtained from the GP:

- 5) If the answer is yes, the instruments need to be quarantined for the rest of the patient’s life or destroyed.
- 6) Contact Marion Lamont in Medical Records [marion.lamont@ggc.scot.nhs.uk](mailto:marion.lamont@ggc.scot.nhs.uk) to get an alert put onto Trakcare for the patient
- 7) If the answer is no then the instruments should be sent for re-processing as normal.

If a patient is identified as having CJD/vCJD either as an inpatient or via notification from Public Health then an alert should be put on Trakcare.

Public Health follows an algorithm which identifies the look back period. They may ask for assistance with reviewing case notes It is at the ICT’s discretion whether they participate in this or not.

### **BLOOD TRANSFUSION**

From April 2004 people who have received a blood transfusion in the UK since 1980 became ineligible to donate blood due to concerns about CJD/vCJD.

Some patients confuse being told they cannot donate blood with being at risk of CJD/vCJD - they are not and require no extra precautions during surgery.