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		Effective From	June 2021
	<b>THE MANAGEMENT OF PATIENTS WITH TRANSMISSIBLE SPONGIFORM ENCEPHALOPATHY (TSE) INCLUDING ALL FORMS OF Creutzfeldt-Jakob Disease (CJD)</b>	Review Date	June 2023
		Version	8
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### SOP Statement

To ensure all relevant clinical staff are aware of the risks associated with prion disease and take appropriate steps to prevent the risk of transmission when clinical interventions are to be undertaken.

This SOP applies to all staff employed by NHS Greater Glasgow & Clyde and locum staff on fixed term contracts.

### KEY CHANGES FROM THE PREVIOUS VERSION OF THIS SOP

- Minor wording changes only

### Document Control Summary

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Lead Manager	Board Infection Control Manager
Responsible Director	Board Medical Director

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## 1. Responsibilities

### All staff must:

- Follow this SOP.
- Inform a member of the Infection Prevention and Control Team (IPCT) if this SOP cannot be followed.
- Report to line managers any deficits in relation to knowledge of Transmissible Spongiform Encephalopathy (TSEs), facilities/ equipment or incidents that may have resulted in cross-contamination.

### Managers must:

- Ensure if appropriate that all staff have education/ training on the principles of managing patients with TSEs.
- Ensure that adequate resources are in place to allow for the recommended infection control measures such as Personal Protective Equipment (PPE) to be implemented.
- Support staff in any corrective action or interventions if an incident occurs that may have resulted in cross-contamination.

### The Infection Prevention and Control Team (IPCTs) must:

- Provide education opportunities for staff on the contents of this SOP.
- Act as a resource for guidance and support when advice on TSE/ Creutzfeldt-Jakob Disease (CJD) is required.
- Provide advice on individual risk assessments for TSE/ CJD decisions.
- Keep this SOP up-to-date.

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## 2. Introduction

TSEs are rare neurodegenerative conditions that include:

- Creutzfeldt–Jakob Disease

CJD is the abbreviation used throughout this document as the other TSEs are very rare and the best practice principles will apply equally to these conditions.

CJD is a progressive, fatal neurological disease that belongs to a wider group of neurodegenerative disorders known as transmissible spongiform encephalopathies (TSEs) or prion diseases. TSEs affect humans and animals. Traditionally, there are three aetiological categories of CJD.

- Sporadic CJD (85–90% of cases) is of unknown aetiology. Sporadic CJD has a worldwide distribution, with a relatively uniform annual incidence of about 1 in 1 million people.
- Inherited CJD (10–15% of cases) is associated with coding mutations, insertions or deletions in the prion protein gene.
- Iatrogenic CJD (less than 1% of cases) arises from accidental exposure to human prions through surgical or medical procedures.

CJD patients typically present with rapidly progressive dementia, usually accompanied by myoclonus and cerebellar ataxia. Most patients die within 4 months of disease onset, in a mute and immobile state

A variant form of CJD was identified in 1996 which was described as being identical to Bovine Spongiform Encephalopathy (BSE). It was thought to have been transmitted to humans by eating contaminated meat products. Other instances of transmission of CJD have been described via receiving blood products and occasionally through instruments contaminated with CJD.

Unlike micro-organisms, prions are not destroyed by conventional methods of decontamination and sterilisation, therefore a risk assessment has to be undertaken before any clinical procedure where there is considered to be a risk of potential transmission. (See [Appendix 1 Algorithm](#))

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The guiding principle in all cases is the attention to:

“best infection control practice” and well informed healthcare workers (HCWs) as to the risk.

The current expert UK CJD guidelines are regularly reviewed and updated especially as more evidence becomes available.

### 3. General Information

#### 3.1. Identified forms of Creutzfeldt-Jakob Disease (CJD) Classical CJD

##### **Familial (inherited)**

found in first-degree relatives

##### **Sporadic**

occurs in 1:1,000,000 of the population with no apparent risk factors

##### **Iatrogenic CJD (particularly related to tissue procedures that we no longer perform in the UK)**

Worldwide, cases of iatrogenic CJD have been associated with the administration of hormones prepared from human pituitary glands and dura mater preparation and one definite case has been reported associated with a corneal graft (iatrogenic transmission has also been identified following neurosurgical procedures with inadequately decontaminated instruments or EEG needles.

##### **Variant CJD (vCJD)**

Found to be pathologically identical to BSE. Clinical presentation differs from Classical forms of CJD. There is evidence that vCJD can be transmitted via exposure to contaminated blood/ blood products. There is a theoretical risk of transmission of vCJD from contaminated surgical instruments.

It is important to differentiate between types of prion disease as the IPC and PH actions may vary depending on type of CJD.

#### 3.2. Categorisation of cases and at risk groups

**Cases are categorised by type of CJD and whether they are confirmed cases or ‘at risk’ individuals.**

**Cases are symptomatic patients who fulfil the diagnostic criteria for *definite, probable or possible* sporadic, familial or acquired CJD as described above.**

**Patients in risk groups do not have symptoms of CJD, rather they have been**

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**characterised as at risk on the basis of a family history or genetic testing, or a previous exposure.**

### 3.3. Reportable disease

The patient's clinician will report any patient suspected on clinical grounds of having vCJD/ CJD to the Clinical Team at the National Surveillance Unit in Edinburgh Tel: 0131 332 2117. Patients identified as at risk of CJD (see below) should be reported to the Public Health Protection Unit (PHPU) 0141 201 (6)4917 e-mail [PHPU@ggc.scot.nhs.uk](mailto:PHPU@ggc.scot.nhs.uk) who will report them to HPS.

### 3.4. Questions to be asked of all patients undergoing Surgery/ Endoscopy

All patients undergoing an invasive procedure will be asked the single question, i.e. they will be asked if they have been notified that they are at risk of CJD for public health purposes. All patients must be asked when being consented for any kind of surgery/ endoscopy. Subsequent actions depend on the patient's response and the risk status of the tissues involved.

**Procedures should not be delayed whilst information is being collected and clinicians should be careful not to prejudice overall patient care.**

### 3.5. There are extra questions that need to be asked of all patients undergoing invasive procedures involving contact with high-risk tissues. High risk tissues are found in the brain and back of the eye. (see Appendix 1).

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

- Brain
- Spinal cord
- Implanted dura mater grafts prior to 1992
- Cranial nerves, specifically: the entire optic nerve, only the intracranial components of the other cranial nerves
- Cranial nerve ganglia
- Posterior eye, specifically: posterior hyaloid face, retina, retinal pigment epithelium, choroid, subretinal fluid, optic nerve
- Pituitary gland

## 4. Transmission Risk

Direct person-to-person spread of CJD and vCJD has not been shown to be a risk. Epidemiological evidence suggests that standard infection control precautions should be undertaken for all caring needs of CJD cases or those deemed at risk for CJD/ vCJD.

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Since 1998 a series of measures have been put in place to reduce/remove the risk of vCJD from blood, blood products, tissues and transplant material.

Patients who have received treatment abroad may not have received the same standards of healthcare, therefore a more cautionary approach may need to be taken e.g. a more detailed medical history.

#### 4.1. Transmission based precautions for cases of CJD and those identified as at risk

Ward procedures and normal routine clinical contact do not pose a risk to HCWs, relatives or others in the community. These patients may be nursed in the open ward areas or in community settings. Additional precautions would only be required if specific interventions were to be undertaken involving contact with high or medium risk tissues.

For any procedure involving the likelihood of aerosols or splashing, the following should be worn:

- disposable aprons/ waterproof gowns
- eye protection/ and masks or visors
- gloves

These should be disposed of as clinical waste at the end of the procedure.

##### 4.1.1. Body fluids

Current evidence suggests there is no additional risk in saliva, excreta and other body secretions and these should be treated with the standard infection control precautions. However it is recommended that only trained staff that are aware of the hazards should carry out invasive procedures that might lead to contact with infective tissues.

##### 4.1.2. Spillages

Standard infection control precautions for body fluid spillages should be used. Treat cerebrospinal fluid spillages the same as a blood spillage.

#### 5. Clinical Interventions

When a patient is identified as at risk or the risk remains unknown via the single question and/or supplementary questions and the invasive procedure involves contact with high-risk tissues, the instruments used should be either

- single use
- quarantined after use if re-usable (and destroyed if the risk is confirmed)
- rarely, kept for exclusive use on the same patient.

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For further details see **Annex J** at:

<https://www.gov.uk/government/publications/guidance-from-the-acdp-tse-risk-management-subgroup-formerly-tse-working-group> (**see Appendix 1**).

For those patients where CJD is a possible diagnosis or asymptomatic patients identified as being at risk:

- Contact the IPCT who will in turn contact PHPU. PHPU will inform HPS for surveillance purposes.
- The patient's GP should be informed and advised 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 surgical, medical or dental procedures.
- The IPCT will inform medical records so that the electronic records can be flagged.
- The IPCT and Public Health will work together to identify any previous procedures which require to be reported to HPS.
- For patients who have been newly identified as being at increased risk if CJD, the IPCT give the patient infection prevention and control advice.

### 5.1. NICE Guidance

The National Institute for Clinical Excellence (NICE) has recommended a number of steps to prevent transmission of CJD/ vCJD from those who were potentially exposed from contaminated beef to those who were not.

NICE guidance covers management of all patients undergoing procedures involving instruments and endoscopes that might pose a risk of transmission of CJD/vCJD. It does not cover dental procedures. The guidance includes recommendations for invasive procedures involving contact with high-risk tissues. Appropriate measures should be in place to reduce the risk.

- A separate pool of neuroendoscopes and re-usable surgical instruments should be used on children and adults born since 1 January 1997 and who have not previously undergone procedures involving contact with high-risk tissues (before guideline implementation).

The most up-to-date version of this SOP can be viewed at the following website:  
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<https://www.nice.org.uk/guidance/ipg196/documents/ipg196-patient-safety-and-reduction-of-risk-of-transmission-of-creutzfeldtjakob-disease-cid-via-interventional-procedures-guidance2>

## 5.2. Dentistry

The risk of transmission of infection from dental instruments is thought to be very low provided optimal standards of infection prevention and control and decontamination are maintained. However further guidance on the use of endodontic instruments is advised in the CMO and Chief Dental Officer's letter of April 2008 (CMO (2007)5). Summary advice:

**Endodontic reamers and files are treated as single-use. Single-use policies for these and other devices specified as single-use (e.g. matrix bands) are rigorously applied. Highest standards of decontamination are observed for all re-usable instruments. Manufacturers' decontamination instructions are followed for all instruments and decontamination equipment.**

## 5.3. Invasive procedures

Ensure all procedures involving access to the subarachnoid space are undertaken with "single-use" instruments only, e.g. lumbar puncture including access to lumbar or extra ventricular drains and neuro-radiological procedures. These should only be undertaken by trained staff who are fully aware of the risks. The National CJD Unit and theatre staff must be informed in advance of any proposed biopsy request on high-risk tissue. These samples must be marked "DANGER of INFECTION". Ensure theatre staff are aware of whether the specimen needs to be fixed or frozen for CJD.

Certain procedures involve contact with high-risk tissues and therefore additional precautions need to be taken to prevent cross-infection.

### 5.3.1. Endoscopy

**Full detailed Guidance on all endoscopic procedures can be found within Annex F:**

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/209765/Annex\\_F\\_-\\_Endoscopy.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/209765/Annex_F_-_Endoscopy.pdf)

It is important that the full guidance is checked and adhered to. The following is a summary only.

The guidance given by the Medical Devices Agency (MDA) 2002(05) should be followed for all endoscopic procedures.

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The main points include:

- Full traceability of the endoscope and any additional non-disposable devices used during the procedure.
- Where possible any cleaning tools and additional devices should be of single-use and discarded as clinical waste after the procedure.

For non neuro endoscopy on a person identified as at risk via the single question, for procedures involving contact with medium risk tissue, further information should be sought in the first instance. The IPCT should be contacted, if available and there is time, to assist in a full risk assessment. Generally the risk assessment takes account of the type of CJD/ vCJD of which the patient is at risk; the types of tissue involved and, in some cases, whether the procedure is invasive. The result of the risk assessment will determine whether special precautions should be used. If a risk is confirmed the instruments used should be either i) single use, ii) quarantined after use if re-usable (and destroyed if the risk is confirmed) or, rarely, iii) kept for exclusive use on the same patient. If the patient answers yes and the IPCT are not available, or time is of the essence, adopt a precautionary approach and quarantine all re-usable instruments until the full risk assessment can be undertaken. If the patient is unable to respond the procedure should go ahead using normal infection prevention and control precautions unless there is other information available on the patient's risk status, e.g. GP letter, or if there is contact with high-risk tissues. In these situations re-usable instruments should be quarantined until the risk is confirmed.

#### 5.4. Surgical Instruments

##### Tonsillectomies

- Single use instruments should continue to be used for routine tonsillectomy for adults (i.e. individuals born before 1997; latest birthday 31/12/1996)
- Re-usable instruments should now be used for routine tonsillectomy for children and adults born after 1996; birthdays from 01/01/1997
- Any re-usable instrument in contact with adeno-tonsillar tissue from a suspected vCJD case or a patient at risk of vCJD should be quarantined until a definitive diagnosis is made or the risk status established and then either permanently removed (if positive vCJD diagnosis, or risk status) or reprocessed according to "best practice" (if definite alternative diagnosis is made or risk status is not established). Instruments used on known cases must be destroyed.

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## General Surgery

For general surgery Annexe M, **Managing v CJD risk in General Surgery and liver Transplantation**

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/209780/Annex M -  
\\_Managing vCJD risk.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/209780/Annex_M_-_Managing_vCJD_risk.pdf)

gives advice on handling instruments that come into contact with medium risk tissues involved in liver transplants and general surgical procedures. It applies to all patients with or at risk of variant CJD undergoing these procedures. For general surgery medium risk tissues include: gut-associated lymphoid tissue, lymph nodes and other organised lymphoid tissues containing follicular structures, appendix, spleen, thymus and tonsil. The guidance applies to surgical procedures where instruments come into contact with the cut surface of such tissues, e.g. operations on the bowel, porta hepatis or cervical lymph nodes. It does not apply to procedures where only lymphatic channels are cut. Further, it applies to patients who have been identified as at risk of variant CJD or those who are symptomatic with probable or definite variant CJD. It does not apply to patients with or at risk of other prion diseases such as familial CJD and sporadic or iatrogenic CJD that is not variant CJD.

- Use single-use biopsy instruments wherever possible.
- Wherever possible use single-use equipment, disposable tips and protective instrument sheaths
- Ensure equipment with a lumen is irrigated as soon as possible after surgery to facilitate adequate decontamination. Also see full endoscope guidance as given above.

### 5.5. Quarantining Instruments

A secure dedicated storage box must be used if instruments are to be quarantined. Clear indication as the identity of the patient must remain with the instruments. Quarantined instruments are normally kept until a definite diagnosis is made or risk status confirmed or refuted, or in some situations, if the instruments are to be used on the same patient at a near future date. If a definite alternative diagnosis is made or the risk status is refuted then the instruments may be put back into circulation after “best practice” decontamination. Full explanation and detailed instructions to be found within Annex E **HOWEVER PLEASE NOTE** in NHS Scotland due to the Glennie Technical Requirements instruments should **NOT** be cleaned prior to quarantining via CDU but should be wiped down with clean water to remove any blood or tissue and dried prior to quarantining.

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

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The decision to destroy surgical instruments will be taken by the local IPCT and the Manager of the Central Decontamination Unit.

**6. Occupational Exposure incidents from patients thought to have definite, probable or possible CJD.**

Avoid sharp injuries and other forms of parenteral exposure, and ensure the safe disposal of sharps and contaminated waste. If incidents occur:

- Gently encourage wounds to bleed.**
- Gently wash with warm soapy water – avoid scrubbing.**
- Rinse, dry and cover with a waterproof dressing.**
- Splashes into the eyes or mouth should be dealt with by thorough irrigation.**

All exposures must be reported using incident reporting systems (Datix) and subsequently under RIDDOR if medically diagnosed.

**7. General Healthcare**

**7.1. Nursing procedures**

Normal nursing care should be given to all patients with CJD/ TSE. There is no requirement to isolate these patients. Epidemiological evidence supports standard infection control precautions to be satisfactory and posing no risk to staff or relatives.

**7.2. Bed linen and patient's clothing**

No special precautions are needed local policies apply.

**7.3. Visitors**

No restrictions.

**7.4. Childbirth**

Standard infection control precautions apply.

**7.5. Transfer of patients to other wards / healthcare settings**

No restrictions but ensure those receiving the patient are aware of any established risk.

**7.6. Procedures after Death**

[NIPCM Appendix 12](#)

The most up-to-date version of this SOP can be viewed at the following website:  
[www.nhsggc.org.uk/your-health/infection-prevention-and-control](http://www.nhsggc.org.uk/your-health/infection-prevention-and-control)

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### 7.7. Post mortems

For further details please see Annex H:

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

### 7.8. Donation of Organs

Not recommended from any patient with **definite, probable** or **possible** CJD.

## 8. Training and Education for Healthcare Workers (HCW)

All HCWs caring for patients with **definite, probable** or **possible** CJD must have received education on Standard Infection Control Precautions and be aware of this SOP. All HCWs undertaking biopsy, blood and lumbar puncture samples from patients with **definite, probable** or **possible** CJD, or from those at risk of CJD, must be trained to do so and be aware of the CJD SOP and also be aware of the need to use single-use equipment.

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## 9. References

Advisory Committee on Dangerous pathogens. Spongiform Encephalopathy Advisory Committee (2003) Transmissible spongiform Encephalopathy Agents: safe working and the prevention of infection Guidance for Health care workers. HMSO

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British Dental Association Fact file (2000) Creutzfeldt –Jakob Disease British Dental Association

National Institute for Health and Clinical Excellence: patient safety and reduction of risk of transmission of Creutzfeldt-Jakob disease (CJD via interventional procedures. November 2006 (Guidance endorsed by NHS QIS for implementation by NHS Scotland)

“Endoscopy and individuals at risk of vCJD for public health purposes” A consensus statement from the British Society of Gastroenterology Decontamination Working Group and the ACDP TSE Working Group Endoscopy and vCJD Sub-Group (November 2005)

## Bibliography

R.L.Baxter et al. (2006) Quantitative analysis of residual protein contamination on reprocessed surgical instruments Journal of Hospital Infection 63, 439-444

## 10. Websites

<https://www.gov.uk/search?q=tse&tab=government-results>

<https://www.hps.scot.nhs.uk/a-to-z-of-topics/creutzfeldt-jakob-disease/>

<http://www.cjd.ed.ac.uk/>

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## Appendix 1 – CJD Risk Assessment

### a) Introduction

The following risk assessment includes a generic form and associated algorithm for administering the single question and/ or the single question and at risk question and, as appropriate, questions relevant for implementation of the NICE guidance.

The clinician undertaking the pre-surgery assessment should also:

- Check the patient’s medical notes and/ or referral letter for any mention of CJD or vCJD status.
- Consider whether there is a risk that the patient may be showing the early signs of CJD or vCJD.

### b) CJD Risk Assessment

Name	Address Use Label	CHI number	Date
<p>CJD is a very rare, rapidly progressing disease of the nervous system that is caused by an abnormal protein (a prion). It is only transmissible if tissue (mainly the brain) from an infected person or animal enters the body of another. CJD is <u>not</u> spread by social contact, coughing, sneezing, kissing, sexual intercourse, childbirth or breast-feeding. Doctors, nurses, relatives and others caring for patients with CJD are not at risk of contracting CJD.</p> <p>To reduce the chance of spreading CJD we need to identify patients whose risk of developing CJD may be increased. <b>The treatment of such patients will not be affected in any way, but appropriate measures to prevent transmission to other patients via surgical instruments will be taken.</b></p>			
<p><b>How to use this flow sheet:</b></p> <p>CJD risk assessment should be performed for all patients undergoing endoscopy or surgery. This applies to both elective and emergency procedures. When it is not possible to assess the risk in advance, (e.g. before emergency procedures on very ill or unconscious patients), for procedures involving contact with high-risk tissues, re-usable instruments should be quarantined pending obtaining the relevant information from the patient’s relatives or General Practitioner. For invasive procedures which do not involve contact with high-risk tissues only the single question is asked. In this situation when the patient is unable to respond to the single question and no other information is available the procedure should go ahead using standard infection control precautions. If the patient says yes to the single question but the IPCT are not available to assist in the risk assessment the procedure should go ahead and re-usable instruments should be quarantined</p>			

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pending full risk assessment as soon as possible.

**c) Invasive procedure involving contact with low or medium risk tissue only:**

**Ask the Single question: Responses and associated actions**

Question:	Patient's Response	Action
<b>Have you been notified that you are at risk of CJD for public health purposes?</b>	<b>No</b>	Surgery or endoscopy should proceed using standard infection control procedures unless the procedure is likely to lead to contact with high-risk tissue.
	<b>Yes</b>	<p>Ask the patient to explain further. Contact the IPCT, if available and there is time, to assist in carrying out a full risk assessment.</p> <p>For an invasive procedure on a person identified as at risk via the single question, for procedures involving contact with medium risk tissue, further information should be sought in the first instance.</p> <p>Generally the risk assessment takes account of the type of CJD/ vCJD of which the patient is at risk; the types of tissue involved and, in some cases, whether the procedure is invasive. The result of the risk assessment will determine whether special precautions should be used.</p> <p>If a risk is confirmed the instruments used should be either i) single use, ii) quarantined after use if re-usable (and destroyed if the risk is confirmed) or, rarely, iii) kept for exclusive use on the same patient (most commonly endoscopes) in line with the national CJD guidance (generally Annexe F and Annexe M).</p> <p>If the risk is not confirmed they should return to circulation after normal decontamination procedures and a check of the integrity of the instrument.</p> <p>If the patient answers yes to the single question and the IPCT are not available, or time is of the essence, the procedure should go ahead and adopt a precautionary approach and quarantine all re-usable instruments until the full risk assessment can be undertaken.</p> <p>For further details See Annex J at: <a href="https://www.gov.uk/government/publications/guidance-from-the-acdp-tse-risk-management-subgroup-formerly-tse-working-group">https://www.gov.uk/government/publications/guidance-from-the-acdp-tse-risk-management-subgroup-formerly-tse-working-group</a></p> <p>Other actions and public health advice for those patients where the risk is confirmed:</p> <ul style="list-style-type: none"> <li>• Contact the IPCT (who will contact PHPU) (PHPU will inform HPS for surveillance purposes).</li> <li>• The IPCT or Public Health will discuss the risk with the patient (using patient information leaflet) and give the patient the infection control and public health advice. The patient should be advised: <ul style="list-style-type: none"> <li>• To inform healthcare staff if they need to undergo an invasive surgical, medical or dental procedure;</li> <li>• To inform a family member or someone close to them, in case they need emergency surgery or endoscopy in the future.</li> <li>• Not to donate blood, organs or tissues, including bone marrow, sperm, eggs or breast milk.</li> </ul> </li> <li>• The patient's GP should be informed and advised 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 surgical, medical or dental procedures.</li> <li>• The IPCT will inform medical records so that the electronic records can be flagged. The IPCT and Public Health will work together to identify any previous procedures which require to be</li> </ul>

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		reported to HPS.
	<b>Unable to respond</b>	Surgery or endoscopy should proceed using standard infection control procedures <b>unless</b> the procedure is likely to lead to contact with high-risk tissue.

**d) Invasive procedure involving contact with high-risk tissues :**

**The single question and at risk questions:**

Question		Notes	Response	Actions, if yes or unable to respond
1.	<b>Single question</b> Have you been notified that you are at risk of CJD for public health purposes?		If yes to any of the questions or unable to respond (and insufficient time to obtain the information from family or GP).	The instruments used should be either i) single use, or ii) quarantined after use if re-usable or, rarely, iii) kept for exclusive use on the same patient. For further details See Annex J at: <a href="https://www.gov.uk/government/publications/guidance-from-the-acdp-tse-risk-management-subgroup-formerly-tse-working-group">https://www.gov.uk/government/publications/guidance-from-the-acdp-tse-risk-management-subgroup-formerly-tse-working-group</a>
2.	Have you a history of CJD or other prion disease in your family? If yes, please specify.	Patients should be considered to be at risk from genetic forms of CJD 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 genetic CJD or other prion disease. iii) Two or more blood relatives affected by CJD or other prion disease.	Follow actions as stated.	If this risk is confirmed quarantined re-usable instruments require to be destroyed. If it is not confirmed they should return to circulation after normal decontamination procedures and a check of the integrity of the instrument.
3.	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 , and iii) whether the	Recipients of hormone derived from human pituitary glands, e.g. growth hormone or gonadotrophin, have been identified as at increased risk of sporadic 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		For those patients where the risk is confirmed:  <ul style="list-style-type: none"> <li>▪ Contact the IPCT (who will contact PHPU) (PHPU will inform HPS for surveillance purposes).</li> <li>▪ The IPCT or Public Health will discuss the risk with the patient (using patient information leaflet) and give the patient the infection control and public health advice. The patient should be advised:               <ul style="list-style-type: none"> <li>○ To inform healthcare staff</li> </ul> </li> </ul>

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[www.nhsggc.org.uk/your-health/infection-prevention-and-control](http://www.nhsggc.org.uk/your-health/infection-prevention-and-control)

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	treatment was received in the UK or in another country	human-derived gonadotrophin was discontinued in 1973 but may have continued in other countries after this time.		<p>if they need to undergo an invasive surgical, medical or dental procedure;</p> <ul style="list-style-type: none"> <li>o To inform a family member or someone close to them, in case they need emergency surgery or endoscopy in the future</li> <li>o Not to donate blood, organs or tissues, including bone marrow, sperm, eggs or breast milk.</li> </ul> <ul style="list-style-type: none"> <li>▪ The patient's GP should be informed and advised 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 surgical, medical or dental procedures.</li> <li>▪ The IPCT will inform medical records so that the electronic records can be flagged.</li> <li>▪ The IPCT and Public Health will work together to identify any previous procedures which require to be reported to HPS.</li> </ul> <p>Patients who are at increased risk of genetic forms of CJD should be offered the opportunity of referral to the National Prion Clinic, based at the National Hospital for Neurology and Neurosurgery, Queen Square, London:  <a href="http://www.nationalprionclinic.org/">http://www.nationalprionclinic.org/</a> Patients who are at increased risk of sporadic CJD due to receipt of human-derived growth hormone or gonadotrophin should be offered the opportunity of referral to the UCL Institute of</p>
4.	Have you ever had surgery on your brain or spinal cord?	(a) Individuals who underwent intradural brain or intradural spinal surgery before August 1992 who received (or might have received) a graft of human-derived dura mater are "at increased risk" of transmission of sporadic CJD (unless evidence can be provided that human-		

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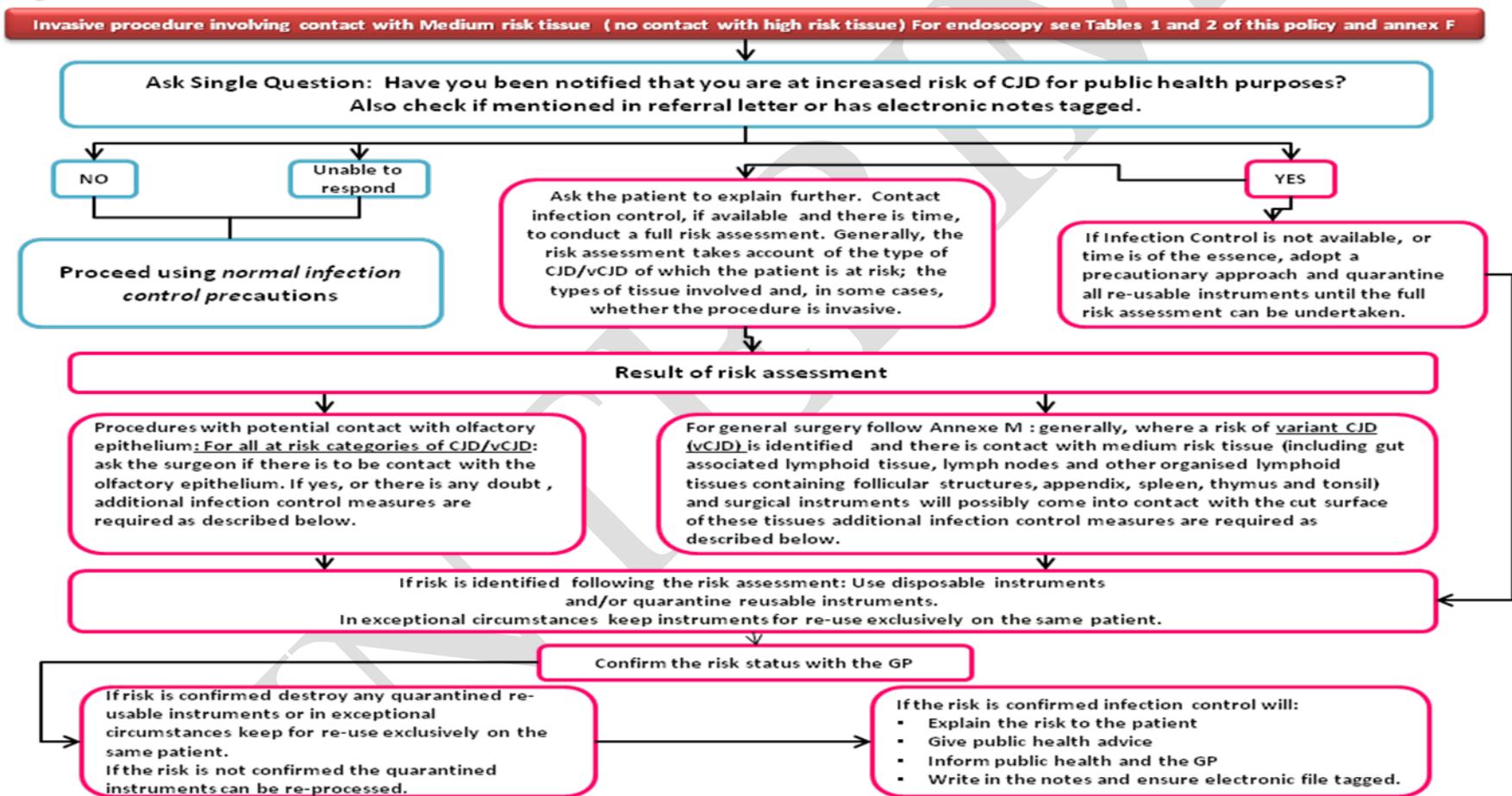
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		derived dura mater was not used). (b) <a href="#">NICE guidance</a> emphasises the need for a separate pool of new neuroendoscopes and reusable surgical instruments for high-risk procedures on patients born since 1st January 1997 and <b>who have not previously undergone high-risk procedures</b> . 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.	Child Health, London. Contact: <a href="mailto:L.Davidson@ich.ucl.ac.uk">L.Davidson@ich.ucl.ac.uk</a> , 020 7404 0536
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### e) CJD Algorithm

CJD Algorithm 1

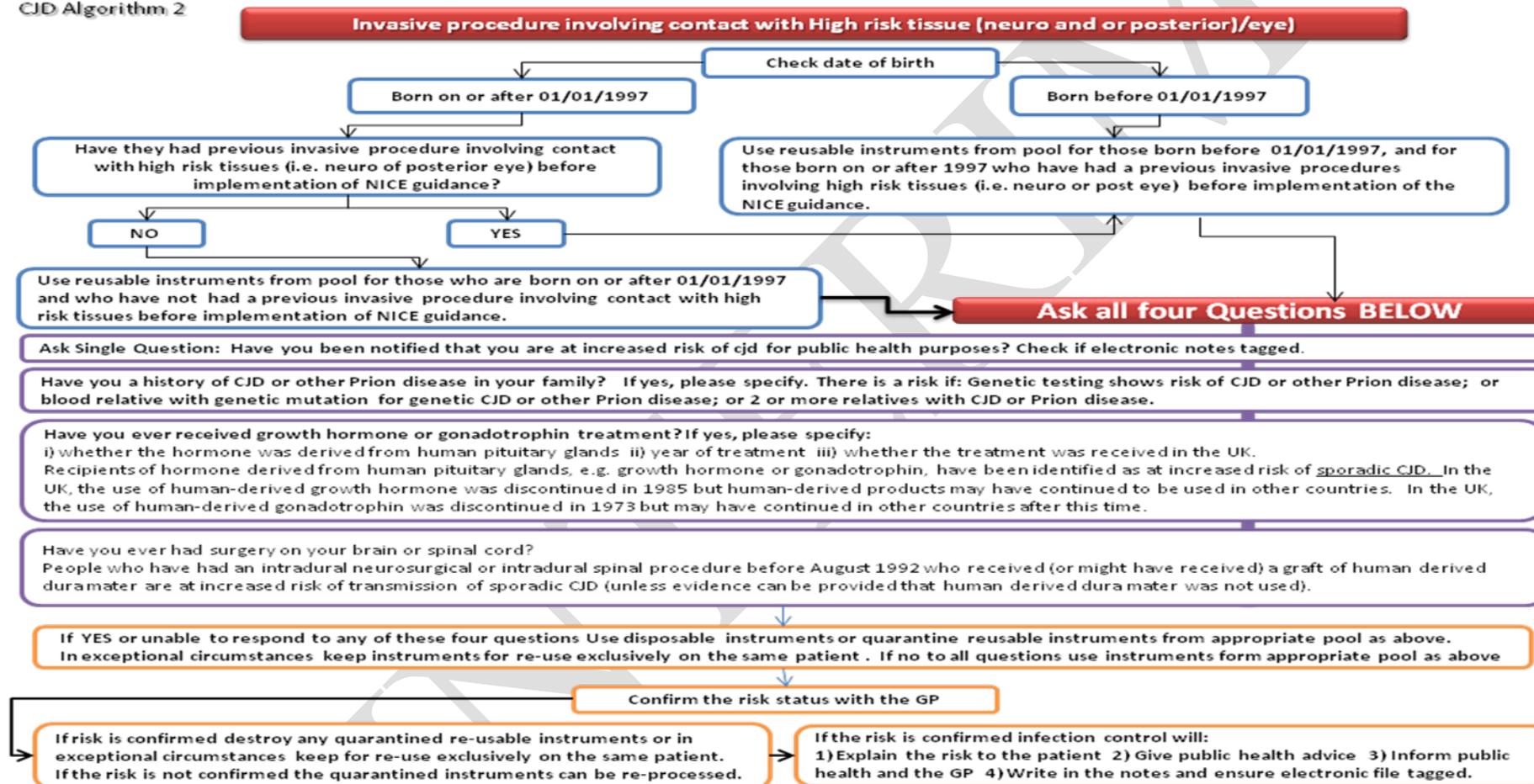


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CJD Algorithm 2



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