



Public Health
England



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Protecting and improving the nation's health

Public health action following a report of a new case of CJD or a person at increased risk of CJD

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Published October 2015
PHE publications gateway number: 2015452

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Guidance documents

Below is a summary of guidance documents concerning the referral of CJD cases, infection control, and investigation and management of surgical incidents.

Guidance title	Purpose of guidance	Published by
National referral of suspected cases of CJD	CJD clinical case reporting, investigation and referral to the national centres in Edinburgh and London.	National CJD Research and Surveillance Unit (NCJDRSU) http://www.cjd.ed.ac.uk/
Transmissible spongiform encephalopathy agents: safe working and the prevention of infection	Infection control guidelines: prevention of TSE transmission in healthcare, laboratory and community settings.	Advisory Committee on Dangerous Pathogens (ACDP) https://www.gov.uk/government/publications/guidance-from-the-acdp-tse-risk-management-subgroup-formerly-tse-working-group
Public health action following a report of a new case of CJD or a person at increased risk of CJD (this guidance)	Public health follow up for newly diagnosed cases of CJD and patients identified as at increased risk. Investigation and management of incidents where potential transmission of CJD has occurred through surgical exposure.	Public Health England/Health Protection Scotland https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/367797/Public_health_action_following_a_report_of_a_new_case_of_CJD_or_a_person_at_increased_risk_of_CJD.pdf

Links to reporting forms and factsheets (available on PHE [website](#))

- Form 1:** Procedure lookback and risk assessment
- Form 2A:** High infectivity tissues - potentially contaminated instruments and subsequently exposed patients
- Form 2B:** Medium infectivity tissues - potentially contaminated instruments and subsequently exposed patients
- Form 3:** Incident report
- Form 4:** Enhanced surveillance

CJD factsheets for patients and healthcare professionals

Version control for PHE guidance

Document information	
Title	Public health action following a report of a new case of CJD or a person at increased risk of CJD
Author	Original author 2013 CJD Incidence Panel Guidance Subgroup; Revised and updated by Tristan Childs, October 2015.
Approved by	Public Health England, CJD Section
Version	Version 1.6
Date of Issue	1 October 2015
Document history	
Date	Reason for change
Version 1.1 May 2013	Changes in formatting implemented to Appendix 3
Version 1.2 May 2013	Changes in formatting implemented to the contents page
Version 1.3 Oct 2013	pg. 5 Added final paragraph on follow-up not a requirement of local public health teams, hospitals or trusts but completed by NCJDRSU pg. 9 Changed wording of final sentence to indicate blood donation/transfusion does not need to be investigated locally pg. 28 Updated contact details – the NHS email particularly for the transfer of sensitive personal information from NHS sites
Version 1.4 Jan 2014	pg. 2 Updated table of guidance; now collated into three documents (NCJDRSU, ACDP and PHE guidance) pg. 3 Addition of appendix to contents (Appendix 3: Dealing with patients and incidents involving inherited prion disease) Rearrangement and indexing of subsequent appendices
Version 1.5 Mar 2014	Inserted a VERSION CONTROL document to guidance
Version 1.6 October 2015	pg. 1 Added hyperlinks to CJD forms and factsheets pg. 22 Appendix 3: Updated subsection about public health follow up of patients and incidents involving inherited Prion disease Updated hyperlinks and PHE style formatting throughout the document
Document review plan	
Responsibility for Review	Dr Katy Sinka, CJD Section Head, Public Health England
Next Review Date	As necessary
Next Issue Date	As necessary
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Introduction

This document is intended for use by NHS trusts, hospitals, local health protection teams and health boards. It provides advice and information for the public health follow-up required following a report of:

- a newly diagnosed or suspected case of CJD
- a person at increased risk of CJD
- a surgical procedure carried out on a patient with CJD or at increased risk of CJD where TSE infection control guidelines were not followed

Information about a newly identified case of CJD, a person at increased risk of CJD or a potential surgical incident may come from a variety of sources, but the required public health action is similar. This guidance is intended to support a considered local interpretation and risk assessment of the unique circumstances that may arise.

A surgical incident occurs when a patient with or at increased risk of CJD has had an invasive procedure involving high or medium infectivity tissues for CJD and TSE instrument precautions were not taken. Patients subsequently exposed to the implicated instruments may need to be informed that they are at increased risk of CJD, depending on the specific circumstances. In most cases, incidents relate to invasive procedures that were carried out before the patient was diagnosed or identified as at increased risk.

Rationale

CJD is a rare and fatal neurodegenerative disease associated with accumulation of abnormal prion proteins. There is evidence of person-to-person transmission of CJD through healthcare exposures, including surgical procedures. Prevention of secondary CJD through healthcare interventions presents a particular problem because:

- prion proteins are resistant to conventional decontamination methods
- abnormal prion proteins have been detected in a range of tissues in clinical cases at post-mortem
- there is no reliable method to identify sporadic, iatrogenic or variant CJD infection in patients who are asymptomatic

A precautionary approach is taken towards risk management for surgical exposures.

Public health actions to reduce the risk of secondary transmission of CJD

- removal of contaminated instruments from general use prevents further surgical exposure
- informing exposed patients of their increased risk of CJD enables infection control for future surgical procedures to reduce contamination of further instruments
- notified patients are asked not to donate blood, organs or tissues
- long-term public health surveillance monitors significant developments at a national level

Outline of public health actions

Objective of public health actions:

- prevent secondary transmissions of CJD
- public health surveillance of those at increased risk of CJD

Outline of actions to take

- 1 Follow TSE infection control guidelines for future procedures with a risk of CJD transmission
- 2 Procedure lookback and risk assessment to identify whether a surgical incident has occurred
- 3 Remove from general use any surgical instruments or endoscopes that pose an onward transmission risk
- 4 Identify and inform patients who may have an increased risk of CJD following an incident
- 5 Recording and reporting of incidents

An action plan with timescales should be developed to ensure actions are completed as quickly as practicable.

Roles and responsibilities

The key roles and responsibilities involved are outlined below. The responsibilities may vary depending on the nature of the incident and a degree of flexibility is required when several organisations are working together to manage a complex incident. Where a surgical incident is

identified that involves more than one trust/hospital or more than one health protection team, it is particularly important that there should be agreement on the overall public health management of the incident. However, all organisations involved in the incident will have a shared responsibility to ensure that the incident is appropriately managed through to its conclusion. It is essential that responsibility for actions should be agreed and recorded.

The CJD surgical incident action planner ([Appendix 4](#)) can be used to assign responsibilities and timescales for each action.

Local health protection/public health response

The local health protection/public health team is usually responsible for co-ordinating the public health follow-up of a new diagnosis of CJD, a newly identified patient at increased risk or a potential surgical incident, especially where more than one trust is involved.

Public health follow-up includes:

- reviewing the patient's GP records and the information provided by the local trust or hospital to identify any surgical or invasive procedures the patient has undergone during the relevant lookback period for the type of CJD suspected or diagnosed (see table A and table B in [Appendix 2](#))
- working with the relevant trusts, hospitals or health boards to assess risk for those procedures involving contact with medium or high infectivity tissues
- continued work with the local healthcare response team to agree appropriate public health investigations and actions

Local trust or hospital response

The trust in which an incident has occurred is responsible for taking appropriate actions to manage their instruments and the patients who may have been exposed to infection. These actions include:

- informing the local health protection/public health team of newly identified CJD patients or patients at increased risk of CJD
- collating the information necessary for a risk assessment and a procedure lookback
- tracing the instruments involved in any relevant surgical procedures and documenting their subsequent history of use and decontamination
- removing from general use any surgical instruments or endoscopes that pose an onward transmission risk
- if required, identifying and informing the subsequent patients on whom instruments were used

Infection control teams will usually be part of the local trust or hospital response. If a patient with or at increased risk of CJD is due to undergo an invasive procedure, including endoscopy, infection control teams should follow ACDP TSE infection control guidance, [Infection control of CJD, vCJD and other human prion diseases in healthcare and community settings](#), to assess whether and what precautions are required for the surgical instruments and flexible endoscopes involved.

National CJD Research and Surveillance Unit and blood services

Following a report of a new case of CJD to the National CJD Research and Surveillance Unit (NCJDRSU), blood donation and transfusion history is established through liaison with blood services. This is not required as part of the risk assessment and public health follow up by local health protection and public health teams or hospitals and trusts.

Overview of the identification and management of CJD surgical incidents

A surgical incident has occurred when a patient with, or at increased risk, of CJD has had an invasive procedure involving high or medium infectivity tissues for CJD and where TSE instrument precautions were not taken. Patients subsequently exposed to the implicated instruments may need to be informed that they are at increased risk of CJD, depending on the specific circumstances.

RISK ASSESSMENT → RISK MANAGEMENT → REPORTING → RECORDING

Risk assessment: Identifying a potential surgical incident

The type of CJD the patient has, or the type for which they are at increased risk will determine i) the period of the procedure lookback required, and ii) the range of tissues that pose high and medium infectivity risks.

- 1 Following a report of a new case of CJD/person at increased risk, the local trust should ensure surgical instruments (including endoscopes) that have potentially been in contact with high or medium infectivity tissues for CJD, and have been through fewer than 20 cycles of use, are decontaminated as normal and removed from general use until the situation can be clearly risk assessed.
- 1.1 If the patient is symptomatic, confirm their diagnosis with the neurologist providing their care and classify the CJD type and current status (see table A, [Appendix 2](#)). The diagnostic classification should have been provided by the UK National CJD Research and

Surveillance Unit (NCJDRSU) or, for inherited prion disease, the National Prion Clinic (NPC).

- 1.2 If the patient is at increased risk of CJD, confirm the reason for the increased risk. If necessary, check their increased risk status using the contact details provided (see table B, [Appendix 2](#)).
- 1.3 For symptomatic patients where the CJD type or status is unclear, or patients who may be at increased risk of CJD, but where this has yet to be confirmed, public health actions should still be taken.

For all groups (1.1, 1.2 and 1.3), irreversible actions such as permanent disposal of instruments and notification of subsequently exposed patients ought not to be conducted until the CJD diagnosis or risk status has been confirmed.

- 2 Determine the length of the procedure lookback (see [Appendix 2](#)).
- 3 Conduct the procedure lookback using GP and hospital notes as necessary.
- 4 Assess all invasive procedures identified and categorise as involving tissues of low, medium or high infectivity for CJD (see table C, [Appendix 2](#)). If tissue involvement is uncertain, discuss the details with the clinicians involved as appropriate. If the procedure was done using single use instruments only, there is no risk for onward transmission and the procedure should not be managed as an incident.
- 5 Procedures involving the donation/receipt of organ/tissue (but not blood) should be included in the procedure lookback and advice sought from the CJD Section, Public Health England, as to further action required. Blood donation/transfusion history does not need to be established as part of this risk assessment because this is investigated by the NCJDRSU for symptomatic cases, and at the time of notification for patients identified as at increased risk of CJD.
- 6 Record the details on Form 1: Procedure lookback and risk assessment.
- 7 Decide: Has the patient had any invasive procedures involving high or medium infectivity tissues within the lookback period where TSE instrument precautions were not followed? (See [flowchart](#))

If **no**, this is not an incident, record the results of investigations and close. Decontaminate and return all quarantined instruments to general use.

If **yes**, this is an incident; continue to 'Risk management' below for the public health actions required.

Risk management: Managing potentially contaminated reusable instruments and exposed patients

Tracing reusable instruments and identifying potentially exposed patients will likely involve reviewing theatre, decontamination, hospital and patient records. The aim is to ascertain the subsequent usage of each instrument following a procedure involving high or medium infectivity tissue in an index patient (See **Public health actions: Step 2** for summary tables).

- 8 For all invasive procedures involving high or medium infectivity tissues on the index patient, review the required records and record the subsequent instrument use and the identity of the patients exposed at each use (the first 10 patients for procedures on high infectivity tissues and first two patients for procedures on medium infectivity tissues). Complete forms 2A and/or 2B (one form for each procedure).
- 9 Keep from general use any instruments that still pose a significant risk for onward transmission. Decontaminate and return to use instruments that do not pose a significant risk for onward transmission.

See **Step 2** for details of when instruments pose a significant onward transmission risk. This depends on the tissues involved in the procedure, the CJD type of the index patient or why they are at an increased risk and the subsequent use and decontamination of the implicated instruments.

Instruments removed from general use can either be destroyed or decontaminated and retained for exclusive use on the index patient. Irreversible actions such as permanent disposal of instruments and notification of subsequently exposed patients ought not to be conducted until the CJD diagnosis or risk status has been confirmed.

Note:

Before an instrument is quarantined it should be first decontaminated to the required standard (see **Annex E** of the TSE infection control guidance).

It is not appropriate to put instruments posing a significant onward transmission risk through additional decontamination cycles in order to return them to use.

If instrument tracing systems cannot identify the specific instruments used on the index patient, any instruments that may have been used and could still pose a significant risk for onward transmission should be considered potentially contaminated and removed from general use as appropriate.

- 10 Identify patients that have been exposed to an increased risk of CJD.

See **Step 2** for details of how many patients should be traced. This depends on the tissues involved in the procedure, the CJD type of the index patient or why they are at an increased risk, and the subsequent use and decontamination of the implicated instruments.

- 11 Decide whether patients have been identified with certainty as exposed and who should be notified.

In some cases, it may not be possible to identify with certainty the subsequently exposed patients (eg because of uncertainty as to which instruments were used). As a general rule, individuals whose exposure is not certain should not be notified.

For patients that can be identified with certainty as exposed, the following outcomes may occur:

- they are traced and notified as at increased risk
- they are traced and found to be deceased
- they are traced and a local decision is taken that it is inappropriate to notify the patient
- the patient cannot be traced

It is the responsibility of the trust (or health board in Scotland) to ensure that the patient is notified as at increased risk of CJD where appropriate. Discuss this decision with local health protection team/public health team as necessary.

- 12 Notify patients as required.

The process will need to be co-ordinated locally. Local health protection teams/public health teams can provide assistance with this process. Notification resources and more information on the notification process are available in **Step 3** and on the PHE [website](#). Notified patients should be reported to the CJD section at PHE (or HPS in Scotland) for public health surveillance purposes.

Reporting

- 13 Report the incident and any patients identified as at increased risk to the CJD section at PHE (or HPS in Scotland).

For all incidents complete Form 3: Incident report.

Where appropriate complete Form 4: Enhanced surveillance.

Return these forms to the CJD section at PHE (or HPS in Scotland).

Recording

- 14 Securely retain incident related documentation.

It is recommended that a clear record is kept concerning the lookback and review carried out to investigate CJD surgical incidents and that these are securely retained. Record retention guidance can be found in [Records Management: NHS code of Practice](#).

- 15 Conduct a root cause analysis (where applicable) and record and disseminate the results to relevant staff.

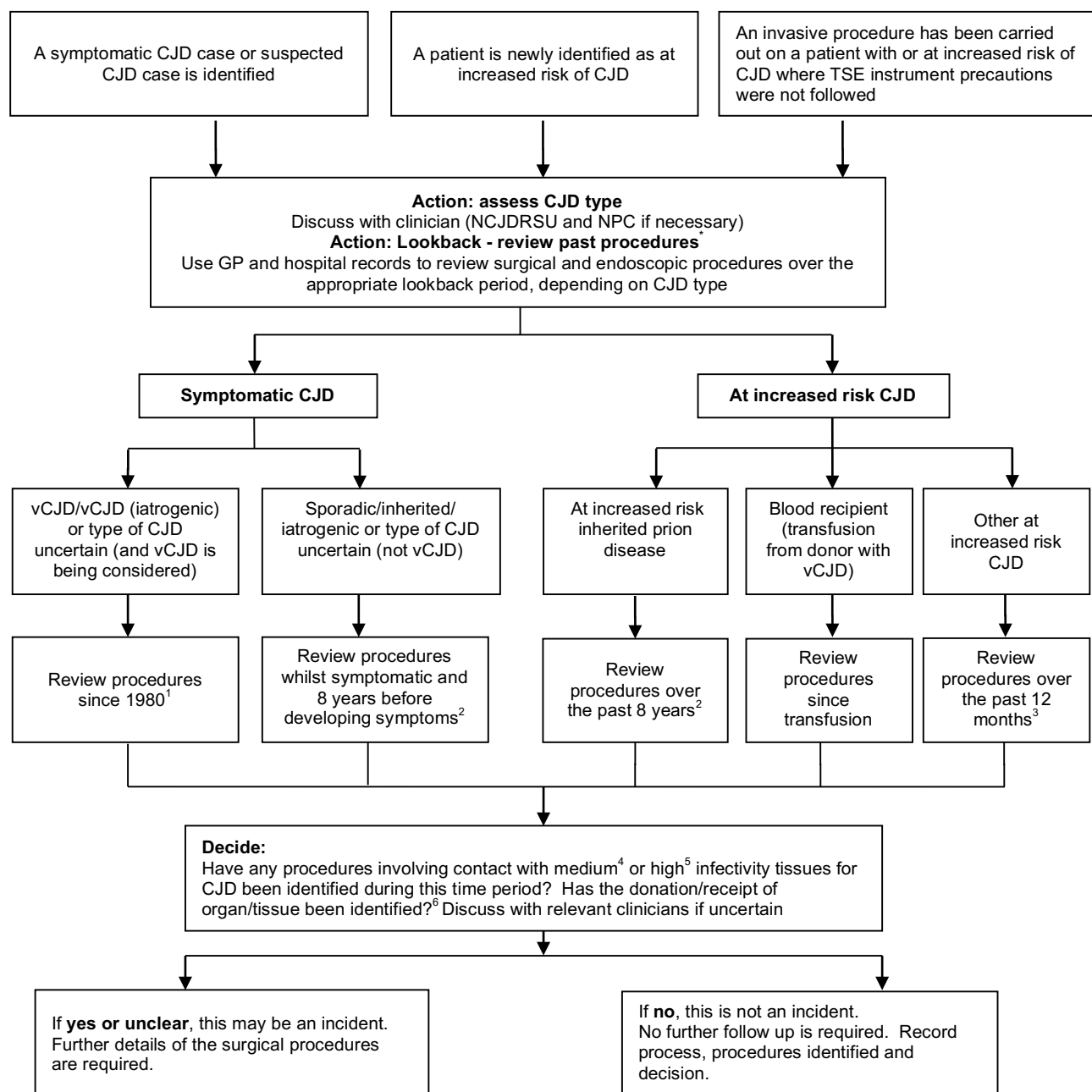
If a surgical incident was the result of an avoidable exposure or if during the course of the lookback and investigation problems are found in tracing instruments or patients, then a root cause analysis may be beneficial in order to assess whether anything could have been done to prevent the incident or to improve systems of recording.

Public health actions

Step 1: Identification of a CJD surgical incident

Follow the flowchart below to assess surgical & endoscopic procedures that have been carried out on people with CJD or at increased risk of CJD.

Flowchart: Identification of a CJD surgical incident



Notes:

*It is not necessary to identify the patients' dental practitioner and review these records – all high street/primary care dental procedures involve only tissues of low infectivity for CJD.

¹ As little is known about the development of tissue infectivity in humans infected with vCJD, please review surgical procedures since 1980, this is the date when first exposure to vCJD through the food chain is estimated.

² Infectivity in sporadic, inherited prion disease and iatrogenic CJD (apart from vCJD) is considered significant only in the last 8 years of the incubation period.

³ 12 months lookback will identify instruments that could potentially still pose a significant onward transmission risk. Notification of patients exposed in these incidents is not required.

⁴ Medium infectivity tissues

All types of CJD: brain; spinal ganglia and olfactory epithelium.

vCJD (and where type uncertain): tonsil, appendix, spleen, thymus, adrenal gland, lymph nodes and gut-associated lymphoid tissues (including the rectum).

⁵ High infectivity tissues

All types of CJD: brain; spinal cord; cranial nerves (specifically the entire optic nerve and the intracranial components of the other cranial nerves); cranial nerve ganglia; posterior eye (specifically the posterior hyaloid face, retina, retinal pigment epithelium, choroid, subretinal fluid, optic nerve); pituitary gland.

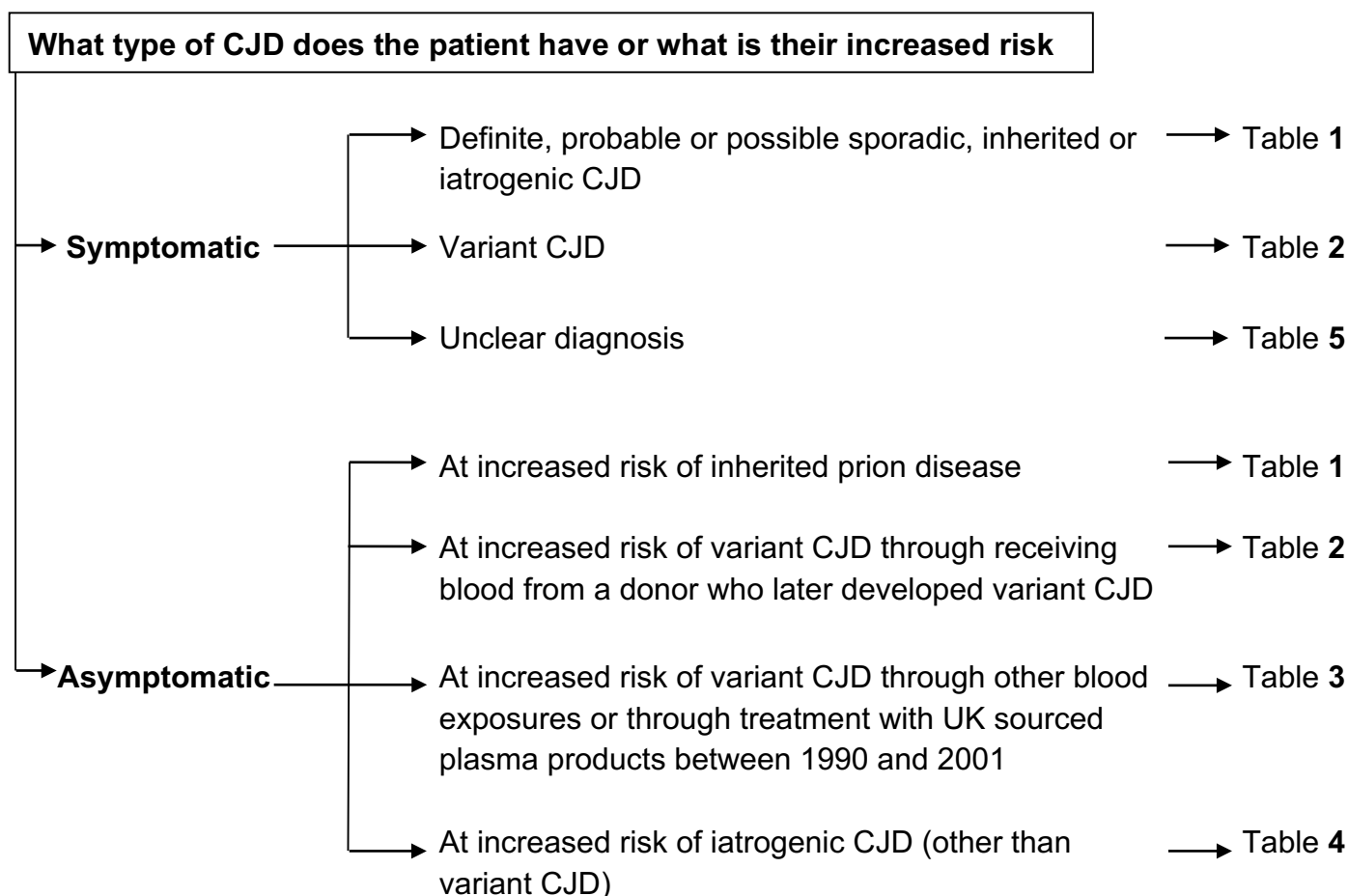
⁶ Procedures involving the donation/receipt of organ/tissue (but not blood) should be included in the procedure lookback and advice sought from the CJD Section, PHE as to further action required. Blood donation/transfusion does not need to be investigated locally.

Step 2: Managing potentially contaminated reusable instruments and exposed patients

Tables 1 to 5 set out the summary of actions to be taken to manage potentially contaminated instruments and patients exposed to a risk of CJD. Actions required are dependent on:

- the CJD type the index patient has or why the index patient is at an increased risk of CJD
- the CJD infectivity of the tissues involved in the index patient procedure
- the number of times the implicated instruments have been used since the index patient procedure*

Use the algorithm below to identify the table of public health actions relevant to the index patient under investigation.



* “Use” for the purposes of this document is defined as use of the instrument(s) on a patient followed by decontamination to an approved standard.

Table 1: Public health actions required for:

Symptomatic patients with:

- sporadic CJD
- inherited prion disease
- iatrogenic CJD*

Asymptomatic patients at increased risk of inherited prion disease

Tissue involved in procedure	Action for instruments is determined by the number of cycles of use and decontamination they have already been through since used on the index patient				Patients exposed to instruments
	Action for surgical instruments by number of uses to date		Action for flexible endoscopes** by number of uses to date		
High infectivity <ul style="list-style-type: none">• Brain• Spinal cord• Cranial nerves• Cranial ganglia• Posterior eye• Pituitary glands	<u>Fewer than 20 uses</u> Destroy or retain for exclusive use on this patient	<u>More than 20 uses</u> Reprocess & return to use	<u>Fewer than 20 uses</u> Destroy or retain for exclusive use on this patient	<u>More than 20 uses</u> Destroy or retain for exclusive use on this patient	10 patients subsequently exposed to instruments in contact with high infectivity tissues should be traced and notified
Medium infectivity <ul style="list-style-type: none">• Spinal ganglia• Olfactory epithelium**	<u>Fewer than 10 uses</u> Destroy or retain for exclusive use on this patient	<u>More than 10 uses</u> Reprocess & return to use	<u>Fewer than 10 uses</u> Destroy or retain for exclusive use on this patient	<u>More than 10 uses</u> Destroy or retain for exclusive use on this patient	2 patients subsequently exposed to instruments in contact with medium infectivity tissues should be traced and notified
Low infectivity All other tissues not listed above	Reprocess & return to use	Reprocess & return to use	Reprocess & return to use	Reprocess & return to use	No patients should be traced and notified

* iatrogenic CJD as a result of receiving human derived growth hormone, gonadotropin or a dura mater graft (excludes patients with iatrogenically acquired variant CJD)

**The advice of the consultant carrying out the endoscopic procedure in the nasal cavity should be sought to determine whether a risk of contamination of the endoscope with olfactory epithelium can be excluded with confidence. If such contamination cannot be excluded, take precautions appropriate for medium infectivity tissues

Note: Before an instrument is quarantined it should be first decontaminated to the required standard (see TSE infection control [guidance](#)).

Table 2: Public health actions required for:

Symptomatic patients with variant CJD

Asymptomatic patients at increased risk of variant CJD through receiving blood from a donor who later developed variant CJD*

A greater range of medium risk tissues should be considered during the risk assessment than for other types of CJD

Tissue involved in procedure	Action for instruments is determined by the number of cycles of use and decontamination they have already been through since used on the index patient				Patients exposed to instruments
	Action for surgical instruments by number of uses to date		Action for flexible endoscopes** by number of uses to date		
High infectivity <ul style="list-style-type: none">Brain or spinal cordCranial nerves or gangliaPosterior eyePituitary glands	<u>Fewer than 20 uses</u> Destroy or retain for exclusive use on this patient	<u>More than 20 uses</u> Reprocess & return to use	<u>Fewer than 20 uses</u> Destroy or retain for exclusive use on this patient	<u>More than 20 uses</u> Destroy or retain for exclusive use on this patient	10 patients subsequently exposed to instruments in contact with high infectivity tissues should be traced and notified
Medium infectivity <ul style="list-style-type: none">Spinal gangliaOlfactory epithelium**Tonsil; appendix; spleenThymus; adrenal glandLymph nodes & gut-associated lymphoid tissues (including the rectum)	<u>Fewer than 10 uses</u> Destroy or retain for exclusive use on this patient	<u>More than 10 uses</u> Reprocess & return to use	<u>Fewer than 10 uses</u> Destroy or retain for exclusive use on this patient	<u>More than 10 uses</u> Destroy or retain for exclusive use on this patient***	2 patients subsequently exposed to instruments in contact with medium infectivity tissues should be traced and notified
Low infectivity All other tissues not listed above	Reprocess & return to use	Reprocess & return to use	Reprocess & return to use	Reprocess & return to use	No patients should be traced and notified

*Or theoretically also through receiving tissue or organs donated by a patient who later developed variant CJD (no known occurrences to date)

**The advice of the consultant carrying out the endoscopic procedure in the nasal cavity should be sought to determine whether a risk of contamination of the endoscope with olfactory epithelium can be excluded with confidence. If such contamination cannot be excluded, take precautions appropriate for medium infectivity tissues

*** Flexible gastrointestinal endoscopes may be suitable for refurbishment by their manufacturers/distributors to allow their return to later use. This refurbishment process may be considered as an alternative to quarantining the instrument if a flexible gastrointestinal endoscope has been used in the performance of an invasive procedure in patients at risk of vCJD because they received blood from a donor who later developed vCJD. Refurbishment is not available for endoscopes that have been used for invasive endoscopy in patients with definite or probable vCJD. The decision to undertake refurbishment will be made on a case by case basis by the manufacturer/distributor, taking into account the age and condition of the endoscope, the reprocessing methods and methods of storage following last use. ([annex F](#) TSE infection control guidance)

Note: Before an instrument is quarantined it should be first decontaminated to the required standard (see TSE infection control [guidance](#)).

Table 3: Public health actions required for:

Asymptomatic patients at increased risk of variant CJD through:

- donating blood to someone who later developed variant CJD
- receiving blood from someone who has also given blood to a patient who went on to develop variant CJD
- surgery using instruments previously used on someone who developed variant CJD
- receiving blood from 300 or more donors.
- treatment with UK sourced plasma products between 1990 and 2001(inclusive)

A greater range of medium risk tissues should be considered during the risk assessment than for other types of CJD

Tissue involved in the procedure	Action for instruments is determined by the number of cycles of use and decontamination they have already been through since used on the index patient				Patients exposed to instruments
	Action for surgical instruments by number of uses to date		Action for flexible endoscopes* by number of uses to date		
High infectivity <ul style="list-style-type: none">• Brain or spinal cord• Cranial nerves or ganglia• Posterior eye; pituitary glands	<u>Fewer than 20 uses</u> Destroy or retain for exclusive use on this patient	<u>More than 20 uses</u> Reprocess & return to use	<u>Fewer than 20 uses</u> Destroy or retain for exclusive use on this patient	<u>More than 20 uses</u> Reprocess & return to use	No patients should be traced and notified
Medium infectivity <ul style="list-style-type: none">• Spinal ganglia;• Olfactory epithelium*• Tonsil; appendix; spleen• Thymus; adrenal gland; lymph nodes & gut-associated lymphoid tissues (including the rectum)	<u>Fewer than 10 uses</u> Destroy or retain for exclusive use on this patient	<u>More than 10 uses</u> Reprocess & return to use	<u>Fewer than 10 uses</u> Reprocess & return to use**	<u>More than 10 uses</u> Reprocess & return to use	No patients should be traced and notified
Low infectivity All other tissues not listed above	Reprocess & return to use	Reprocess & return to use	Reprocess & return to use	Reprocess & return to use	No patients should be traced and notified

*The advice of the consultant carrying out the endoscopic procedure in the nasal cavity should be sought to determine whether a risk of contamination of the endoscope with olfactory epithelium can be excluded with confidence. If such contamination cannot be excluded, take precautions appropriate for medium infectivity tissues.

** Flexible endoscopes used on medium infectivity tissues may be returned to general used providing they have been decontaminated according to national standards, with additional infection control precautions as described in the ACDP TSE Infection Control guidance [Annex F](#).

Note: before an instrument is quarantined it should be first decontaminated to the required standard (see TSE infection control [guidance](#)).

Table 4: Public health actions required for:

Asymptomatic patients at increased risk of iatrogenic CJD (other than variant CJD) through

- treatment with growth hormone from UK sourced human pituitary glands (before 1985)
- treatment with gonadotropin derived from human pituitary glands for fertility treatment (before 1973)
- a neurosurgical procedure, or an operation for a tumour or cyst of the spine, before August 1992 who received (or might have received) a graft of human derived dura mater
- surgery using instruments previously used on someone who developed CJD (other than variant CJD)

Tissue involved in procedure	Action for instruments is determined by the number of cycles of use and decontamination they have already been through since used on the index patient				Patients exposed to instruments
	Action for surgical instruments by number of uses to date		Action for flexible endoscopes* by number of uses to date		
High infectivity <ul style="list-style-type: none">• Brain• Spinal cord• Cranial nerves• Cranial ganglia• Posterior eye• Pituitary glands	<u>Fewer than 20 uses</u> Destroy or retain for exclusive use on this patient	<u>More than 20 uses</u> Reprocess & return to use	<u>Fewer than 20 uses</u> Destroy or retain for exclusive use on this patient	<u>More than 20 uses</u> Reprocess & return to use	No patients should be traced and notified
Medium infectivity <ul style="list-style-type: none">• Spinal ganglia• Olfactory epithelium*	<u>Fewer than 10 uses</u> Destroy or retain for exclusive use on this patient	<u>More than 10 uses</u> Reprocess & return to use	<u>Fewer than 10 uses</u> Reprocess & return to use**	<u>More than 10 uses</u> Reprocess & return to use	No patients should be traced and notified
Low infectivity All other tissues not listed above	Reprocess & return to use	Reprocess & return to use	Reprocess & return to use	Reprocess & return to use	No patients should be traced and notified

*The advice of the consultant carrying out the endoscopic procedure in the nasal cavity should be sought to determine whether a risk of contamination of the endoscope with olfactory epithelium can be excluded with confidence. If such contamination cannot be excluded, take precautions appropriate for medium infectivity tissues

** Flexible endoscopes used on medium infectivity tissues may be returned to general use providing they have been decontaminated according to national standards, with additional infection control precautions as described in the ACDP TSE Infection Control guidance [Annex F](#).

Note: Before an instrument is quarantined it should be first decontaminated to the required standard (see TSE infection control [guidance](#)).

Table 5: Public health actions required for:

Symptomatic patients with an unclear diagnosis:

- diagnosis is unclear but not variant CJD
- diagnosis is unclear but variant CJD is still being considered

A greater range of medium risk tissues should be considered during the risk assessment if variant CJD has not been ruled out as a potential diagnosis.

Irreversible actions such as permanent disposal of instruments and notification of subsequently exposed patients should not be conducted until the diagnostic status is clear.

the diagnostic status is clear:

Tissue involved in procedure	Action for instruments is determined by the number of cycles of use and decontamination they have already been through since used on the index patient				Patients exposed to instruments
	Action for Surgical instruments by number of uses to date		Action for flexible endoscopes* by number of uses to date		
High infectivity <ul style="list-style-type: none">• Brain or spinal cord• Cranial nerves or ganglia• Posterior eye• Pituitary glands	<u>Fewer than 20 uses</u> Remove from general use Quarantine pending diagnosis	<u>More than 20 uses</u> Reprocess & return to use	<u>Fewer than 20 uses</u> Remove from general use Quarantine pending diagnosis	<u>More than 20 uses</u> Remove from general use Quarantine pending diagnosis	No patients should be traced and notified until the diagnosis is clear
Medium infectivity <ul style="list-style-type: none">• Spinal ganglia• Olfactory epithelium* <i>If variant CJD is still being considered:</i> <ul style="list-style-type: none">• Tonsil; appendix; spleen• Thymus; adrenal gland• Lymph nodes & gut-associated lymphoid tissues (including the rectum)	<u>Fewer than 10 uses</u> Remove from general use Quarantine pending diagnosis	<u>More than 10 uses</u> Reprocess & return to use	<u>Fewer than 10 uses</u> Remove from general use Quarantine pending diagnosis	<u>More than 10 uses</u> Remove from general use Quarantine pending diagnosis	No patients should be traced and notified until the diagnosis is clear
Low infectivity All other tissues not listed above	Reprocess & return to use	Reprocess & return to use	Reprocess & return to use	Reprocess & return to use	No patients should be traced and notified

*The advice of the consultant carrying out the endoscopic procedure in the nasal cavity should be sought to determine whether a risk of contamination of the endoscope with olfactory epithelium can be excluded with confidence. If such contamination cannot be excluded, take precautions appropriate for medium infectivity tissues.

Note: Before an instrument is quarantined it should be first decontaminated to the required standard (see TSE infection control [guidance](#)).

Step 3: Patient notifications

There are ethical and practical issues around informing people that they might have been exposed to an increased risk of CJD. However, some of those identified may have a relatively high chance of having been exposed to CJD infection. Informing an individual about their risk potentially brings with it a great burden as CJD is a fatal disease for which there is as yet no cure. The aims and rationale for doing so are set out below:

Aims:

- explain what it means to be at increased risk of CJD
- explain the public health precautions to be taken
- offer extra information and support

Rationale:

- minimise possible transmission of CJD infection to others
- enable public health precautions to be taken
- a 12-month procedure lookback can be conducted so that any instrument which may still pose a risk for onwards transmission can be removed from general use

Notification process

The GP is usually best placed to inform patients that they are at increased risk of CJD. In some cases, a specialist doctor who provides ongoing care may inform a patient. In these cases, the specialist should also inform the GP of the patient's increased risk status and that public health actions are required. For most CJD surgical incidents, the small number of patients involved allows a personalised and tailored approach to this communication.

When discussing CJD risks with a patient, it is important to communicate two messages. First that the risk of the patient being infected with CJD is uncertain, but is likely to be low. Second, that it is important that the patient should follow advice to reduce any risk of the infection spreading to other patients. Patients may find the news that they are at increased risk of CJD both distressing and difficult to understand. They may want an absolute guarantee that they will not develop CJD. This is clearly not possible.

Many patients are likely to need more than one opportunity to discuss what this means for them in order to come to terms with what they have been told. It may be helpful to consult a trained counsellor for advice on managing this process. The healthcare professional informing a patient of their increased CJD risk status may wish to arrange follow-up visits to give the patient opportunities to discuss these complex issues with appropriate staff.

Two factsheets, *Who has an increased risk of CJD?* and *Information for people who have an increased risk of CJD*, should be given to patients during these consultations. These are available on the CJD section of the PHE [website](#) (links to the documents are on page 1).

Following notification the patient's GP should:

- record in the patient's primary care records that the patient is at increased risk of CJD, the reason for this, and that special infection control measures may be needed for medical and surgical procedures, including endoscopy (this should only be done once the patient is aware of their exposure to CJD/vCJD)
- inform other clinicians responsible for providing medical care to this patient
- include this information in any referral letters if the patient needs surgery, including specialist dental surgery, or other invasive procedure
- pass this information to any specialist doctors providing ongoing care to the patient
- check if the patient has had surgery in the past year.¹ If this is the case, the GP should tell the local health protection/public health team, who will take action if necessary

Public health actions for people at increased risk of CJD

All people who are at increased risk of CJD are asked to help prevent any further possible transmission to other patients by following this advice:

- don't donate blood. No-one who is at increased risk of CJD or who has received blood donated in the UK since 1980 should donate blood
- don't donate organs or tissues, including bone marrow, sperm, eggs or breast milk
- if you are going to have any medical, dental or surgical procedures, tell whoever is treating you beforehand so they can make special arrangements for the instruments used to treat you if you need certain types of surgery or investigation
- you are advised to tell your family about your increased risk. Your family can tell the people who are treating you about your increased risk of CJD if you need medical or surgical procedures in the future and you are unable to tell them yourself

¹ For patients at risk because they have received blood from a donor who later developed variant CJD this lookback period should extend to the date of the transfusion.

Appendix 1: Background information on CJD

CJD and related human prion diseases are rare and fatal neurodegenerative diseases. Prion diseases are associated with a conformational change in a protein called the “prion protein”. The abnormal form of this protein accumulates in the brain in these disorders and is associated with the death of nerve cells.

Mode of transmission

Most cases of CJD are not a result of transmission. However, there is past evidence of secondary, person-to-person transmission of CJD through healthcare procedures. Transmission has followed past exposures including through corneal transplant, electroencephalogram electrodes, neurosurgical instruments, cadaveric dura mater and pituitary glands. More recently, there has been secondary variant CJD transmission via transfusion of non-leucodepleted red blood cells in the 1990s (four instances) and UK plasma used to produce Factor VIII (one instance).

Risk assessments have considered evidence on tissue infectivity and the effectiveness of routine decontamination for prion protein removal and have concluded that the risks of CJD transmission via surgery appear significant. These conclusions and the lack of a reliable method to identify sporadic, iatrogenic or variant CJD infection during the asymptomatic period continue to support a precautionary approach to the management of potential exposures.

Incidence

The commonest form of human prion disease is sporadic CJD. It affects around one person per million of the population per year throughout the world and accounts for around 85% of all cases of CJD in the UK. The underlying cause is not known. A further 10% of cases are associated with genetic mutations in the prion protein gene and are inherited as autosomal dominant conditions (inherited prion disease). These inherited conditions include Gerstmann-Sträussler-Scheinker syndrome (GSS) and Fatal Familial Insomnia (FFI). Rarer forms of human prion disease include acquired diseases such as Kuru and iatrogenic CJD transmitted between people through medical and surgical exposures. In 1996, a previously unrecognised form of the acquired disease was identified, now known as variant CJD (vCJD). The most likely explanation of vCJD is exposure to the agent that causes Bovine Spongiform Encephalopathy (BSE) in cattle, through consumption of contaminated beef in the 1980s and early 1990s. New diagnoses of variant CJD have declined to very low numbers since 2000. (see <http://www.cjd.ed.ac.uk/data.html>).

Incubation period

Iatrogenic cases: 15 months to more than 30 years

Individuals at increased risk of CJD

Where people have been told by a specialist that they have a risk of developing an inherited form of prion disease, or where a risk assessment determines that an individual has been exposed to a 1% or greater risk of CJD infection through medical procedures, it is recommended that they are informed about this increased risk and asked to take public health precautions to reduce the risk of transmitting infection to other people. The increased risk is additional to the general population vCJD risk through dietary exposure to the BSE agent.

Appendix 2: CJD classifications and procedure lookback period

Table A: Diagnostic classifications^a for symptomatic CJD patients

CJD status and type		Procedure lookback period
<ul style="list-style-type: none"> • Definite • Probable • Possible • Suspected • Unknown 	Sporadic	8 years prior to onset of symptoms and whilst symptomatic
	Inherited prion disease	8 years prior to onset of symptoms and whilst symptomatic, or 8 years prior to knowing of a diagnosis in a blood relative if applicable
	Iatrogenic	8 years prior to onset of symptoms and whilst symptomatic ^b
	Variant (iatrogenic)	Since 1980 ^c
	Variant	Since 1980

- Diagnostic classifications use an expanded WHO case criteria published as [Annex B](#) of the ACDP TSE Guidance
- Iatrogenic CJD is managed as for cases of sporadic CJD and infectivity is considered to be present in tissues up to 8 years prior to the onset of symptoms
- The lookback is to 1980 as opposed to the date of the exposure because infection via consumption of BSE contaminated meat products cannot be excluded

Neurologists, or other responsible clinicians, are asked to report all new and suspected cases of CJD and other prion diseases to the NCJDRSU and the NPC. The clinician caring for the patient should also inform the local health protection/public health team, without delay, of all new and suspected cases (including variant, sporadic, iatrogenic and inherited forms of CJD). This includes cases that do not fulfil the precise clinical criteria for CJD, but where the diagnosis of CJD is being considered and patients who have died prior to diagnosis, whether or not a post-mortem result is available. The report should provide sufficient information to enable public health follow-up. This includes: the name of the patient, the NCJDRSU unique patient number, type of CJD diagnosed or suspected, general practitioner details and what is known of the patient's history of invasive procedure.

The neurologist caring for the patient should be the first point of contact for diagnostic information on symptomatic patients. The diagnostic classification should have been provided by the NCJDRSU or the NPC (inherited prion disease). Irreversible actions such as permanent disposal of instruments and notification of subsequently exposed patients should not be conducted until the CJD diagnosis has been confirmed. The current diagnostic status of a patient can be confirmed by the NCJDRSU, if necessary.

Table B: Classifications for individuals at increased risk of CJD

Reason for increased risk of CJD	Procedure lookback period	Contact for further information risk status
At increased risk of inherited CJD		
People who have been told by a specialist that they have a risk of developing an inherited form of prion disease ^b	8 years	National Prion Clinic, London. Tel: 020 3448 4037 / 4038
At increased risk of iatrogenic CJD (other than variant CJD)		
People who have been treated with growth hormone from UK sourced human pituitary glands (before 1985)	12 months	Institute for Child Health: Tel: 0207 404 0536 Email: p.adlard@ucl.ac.uk
People who have had a neurosurgical procedure, or an operation for a tumour or cyst of the spine, before August 1992 & who received (or might have received) a graft of human derived dura mater	12 months	If it is not possible to establish this exposure precisely from patient records then contact the CJD section at PHE.
People who have had surgery using instruments previously used on someone who developed CJD (other than variant CJD)	12 months	GP is first point of contact. The notification letter will include these details ^a
People who have been treated with human pituitary derived gonadotropin for fertility treatment (before 1973)	12 months	If it is not possible to establish this exposure precisely from patient records then do not consider this patient to be at an increased risk of CJD
At increased risk of variant CJD		
People who have received blood from someone who went on to develop variant CJD ^b	Since transfusion	GP is the first point of contact. The notification letter will include these details ^a
People who have received an organ or tissue from a donor who went on to develop variant CJD ^b <i>[this is a theoretical risk – to date no individuals have been exposed in this way]</i>	Since transplant	GP is the first point of contact. The notification letter will include these details ^a
People who have given blood to someone who went on to develop variant CJD	Since transfusion	GP is the first point of contact. The notification letter will include these details ^a
People who have received blood from	Since	GP is the first point of contact. The

someone who has also given blood to a patient who went on to develop variant CJD	transfusion	notification letter will include these details ^a
People who have received blood from 300 or more donors.	12 months	Action yet to be determined ^d
People who have been treated with UK sourced plasma products between 1990 and 2001. <i>[specifically this will include patients treated with Factor VIII, Factor IX or antithrombin during that period]</i>	12 months	The patient's GP or their specialist haemophilia centre. The UKHCDO ^c holds a register and can advise whether patients have received UK or non-UK sourced products. Tel: 0161 277 7991 or email: support@ukhcdp.org
People who have had surgery using instruments previously used on someone who developed variant CJD	12 months	GP is the first point of contact. Notification letter will include these details

a. If the patient gives consent – the national register of notified patients can be checked for this information,

b. individuals at increased risk of inherited CJD, or at increased risk because they received blood from a donor who later developed CJD are managed differently to other patients for some infection control procedures and public health investigation and management following an incident. This includes the period of lookback and the follow up actions that may be required.

c. UKHCDO: UK Haemophilia Centre Doctors Organisation

d. Contact CJD Section at PHE.

Table C: Tissue infectivity for CJD

Tissue infectivity (CJD type)	Tissues
High (all CJD types)	Brain, spinal cord, cranial nerves (entire optic nerve, intracranial components of other cranial nerves), cranial nerve ganglia, posterior eye (hyaloid face, retina, retinal pigment epithelium choroid, subretinal fluid, optic nerve), pituitary gland
Medium (all CJD types)	Spinal ganglia and olfactory epithelium
Medium (Variant CJD and type uncertain)	Tonsil, appendix, spleen, thymus, adrenal gland, lymph nodes, gut associated lymphoid tissues (including the rectum)
Low (all CJD types)	All other tissues not listed above are considered to have low levels of infectivity for all types of CJD

Appendix 3: Dealing with patients and incidents involving inherited prion disease

Inherited prion disease surgical incidents arise when patients with a genetic mutation for an inherited form of prion disease, or their blood relatives², have previously undergone invasive medical procedures. The index case is one of the following patient groups:

- a) Patients with inherited prion disease. These patients have a disease specific mutation in the prion protein gene, and have symptoms of inherited prion disease.
- b) Asymptomatic patients who have been tested and found to have a disease specific mutation in the prion protein gene.
- c) Any blood relatives² of patients in groups a) and b) who know about their relative's CJD status and their own risk of developing inherited prion disease, but have not themselves been tested for a genetic mutation.

Patients in group b) and c) are at increased risk of inherited prion disease. Nearly all people in group b) and up to 50% of those in group c) will develop inherited prion disease.

Blood relatives who have been tested and do not have a disease specific mutation in the prion protein gene are *not* at increased risk of CJD. Incidents involving these patients should *not* be reported.

Ethical considerations

Some patients choose not to tell their family that they are at increased risk of inherited prion disease. These patients' wishes for confidentiality should be respected.

The CJD Incidents Panel considered this issue and decided that public health measures can only be implemented for patients who are aware of their status. Therefore, public health precautions cannot be implemented for relatives who have not been informed of their risk of developing inherited prion disease. In these situations, family members who are not aware of their status might inadvertently put other patients at risk of prion disease and ethical difficulties may arise.

However, the panel advised that the confidentiality of patients with inherited prion disease, and their wishes with regard to informing others about their condition, override public health protection issues. This is because there have not been any reports of iatrogenic transmission of inherited prion disease. If there is new evidence on infectivity in inherited prion disease, this recommendation will be reviewed.

² A blood relative includes family members related to the index case by common ancestry.

Public health follow-up

A look back to identify invasive procedures that involve medium or high risk tissue carried out within the last 8 years should be undertaken for those in groups a), b) and c). The follow-up process should not involve tracing further family members.

There is an established route of notification for patients who are informed of their risk following a specialist consultation. At diagnosis/detection of a significant genetic mutation, the National Prion Clinic or the patient's neurologist informs the patient's GP who is asked to inform their local CCDC or equivalent. In these circumstances, public health follow-up is required for the individual named in that correspondence.

For further information concerning inherited prion disease, contact the National Prion Clinic.
Tel: 020 3448 4037 / 4038

Appendix 4: CJD Incident Action Plan

Action	Lead responsibility for action	Timescale	Progress

Appendix 5: Glossary

ACDP	Advisory Committee on Dangerous Pathogens (established in 1981) to advise the Health and Safety Executive on all aspects of hazards and risks to workers and others from exposure to pathogens.
ACDP TSE RM SG	ACDP TSE Risk Management Subgroup
'At risk'	At increased risk of CJD or vCJD (see contactable patients)
BSE	Bovine Spongiform Encephalopathy: a slowly progressive and ultimately fatal neurological disorder of adult cattle transmitted by contaminated animal feed.
CCDC	Consultant in Communicable Disease Control
CJD	Creutzfeldt-Jakob Disease: a human transmissible spongiform encephalopathy that can occur in sporadic, familial and acquired (iatrogenic) forms.
CJD surgical incident	A surgical incident has occurred when a patient with or at increased risk of CJD has had an invasive procedure involving high or medium infectivity tissues for CJD and TSE instrument precautions were not taken. Patients subsequently exposed to the implicated instruments may need to be informed that they are at increased risk of CJD, depending on the specific circumstances.
CNS	Central Nervous System: includes the brain, cranial nerves and spinal cord.
Contactable patients	People exposed in an incident who are considered to have a higher risk of acquiring CJD. They should be contacted and informed about their exposure so that action may be taken to prevent any further spread of disease.
CPHM	Consultant in Public Health Medicine
CSF	Cerebrospinal fluid: fluid that bathes the brain and spinal cord.
Decontamination	A process which removes or destroys contamination and thereby prevents micro-organisms or other contaminants reaching a susceptible site in sufficient quantities to initiate infection or any other harmful response.
Definite CJD	An international definition used by the NCJDRSU that refers to the diagnostic status of cases. In definite cases the diagnosis will have been pathologically confirmed, in most cases by post mortem examination of brain tissue (rarely it may be possible to establish a definite diagnosis by brain biopsy while the patient is

	still alive).
Dura mater	The outermost and strongest of the three membranes (meninges) which envelop the brain and spinal cord.
Genetic (Familial) CJD (inherited prion disease)	CJD cases that occur in families, associated with mutations in the PrP gene (10 – 15% of all CJD cases).
HPA	Health Protection Agency (now PHE)
HPS	Health Protection Scotland
HPU	Health Protection Unit
hGH	Human growth Hormone; at one time this was made from pituitaries from human cadavers. This was rarely contaminated with CJD agent, and is now known to have transmitted CJD to a number of those treated with hGH for short stature.
Iatrogenic CJD	Infection with CJD that occurred as the result of a medical procedure.
Lymphoreticular system (LRS)	Lymphoreticular System is referred to because of its possible infectivity in variant CJD. Infectivity has been demonstrated in the lymph nodes, appendiceal lymphatic tissue, spleen and tonsils in variant CJD.
NCJDRSU	National CJD Research and Surveillance Unit: based in Edinburgh and aims to identify and study all cases of CJD in the UK
NPC	National Prion clinic
PHE	Public Health England
Possible CJD	An international definition used by the NCJDRSU that refers to the diagnostic status of cases. Possible cases fulfil certain clinical criteria, but do not meet the criteria for probable or definite cases.
Probable CJD	An international definition used by the NCJDRSU that refers to the diagnostic status of cases. Probable cases fulfil clinical criteria but do not meet the criteria for definite cases.
Sporadic CJD	Cases of CJD that occur at random throughout the world and have no known cause. This is the commonest form of CJD.
TSE	Transmissible Spongiform Encephalopathy: a group of fatal diseases of the neurological system characterised by spongy degeneration of the brain with progressive dementia. Examples include CJD in humans, and scrapie and BSE in animals
vCJD	Variant Creutzfeldt-Jakob disease: identified in 1996 as a previously unrecognised form of CJD, having a novel pathology and consistent disease pattern. Exposure to BSE is the most likely

explanation for the emergence of the disease. It was previously known as nvCJD (new variant CJD).

Contact details

The clinician caring for the patient is the first point of contact for diagnostic information on symptomatic patients.

For enquiries relating to implementation of the guidance in England, Wales and NI:

CJD Section, Public Health England

CJD Section

Public Health England

61 Colindale Avenue

London NW9 5EQ

Tel 0208 327 6090

Email: cjd@phe.gov.uk or PHE.cjd@nhs.net

Web: <https://www.gov.uk/government/collections/creutzfeldt-jakob-disease-cjd-guidance-data-and-analysis>

The CJD Section is based in Colindale, London. The CJD Section provides national advice and support to prevent the potential spread of CJD in healthcare settings. The CJD Section aims to:

- monitor the transmission of CJD to people identified as having an increased risk of infection
- reduce the risk of iatrogenic transmission of the CJD agent between patients
- describe the prevalence of CJD in the UK through studies of abnormal prion protein
- provide information for planning and evaluating risk reduction policies

To achieve these aims, the CJD section:

- provides advice to local trusts, health boards and health protection teams on the implementation of the CJD incidents guidance
- co-ordinates studies of the prevalence of abnormal prion protein
- performs enhanced surveillance on patients at increased risk of CJD

For enquiries relating to implementation of the guidance in Scotland:

Health Protection Scotland, Health Services Scotland

CJD

3rd Floor

Meridian Court

5 Cadogan Street

Glasgow G2 6QE

Tel 0141 282 2919

email NSS.HPSInfectionControl@nhs.net

Web: <http://www.hps.scot.nhs.uk/>

For enquiries relating to symptomatic cases of CJD:

National CJD Research and Surveillance Unit, Edinburgh

The National CJD Research & Surveillance Unit

Western General Hospital

Crewe Road

Edinburgh EH4 2XU

Tel 0131 537 2128

Web: www.cjd.ed.ac.uk

The National CJD Research & Surveillance Unit (NCJDRSU) is funded by the Department of Health in England and the Scottish Government Health Department to identify, classify and investigate prion diseases in the UK. Based at the Western General Hospital in Edinburgh, the NCJDRSU aims to monitor the characteristics of all forms of CJD, to identify trends in incidence rates, to study risk factors for the development of disease and to contribute to improving the quality of care for those with CJD. The NCJDRSU works closely with the UK government health departments, the national blood authorities, the national public health agencies, as well as local health protection/public health teams, to provide advice where needed. The NCJDRSU also receives research funding individual, charitable, national and international sources.

For enquiries relating to inherited prion disease cases and relatives of these patients:

National Prion Clinic

National Prion Clinic

The National Hospital for Neurology & Neurosurgery

Queen Square

London

WC1N 3BG

Tel: 020 3448 4037 / 020 3448 4038

Web: <http://www.prion.ucl.ac.uk/clinic-services/>

The National Prion Clinic (NPC) is the national referral centre for prion disease and is part of the University College London Hospitals NHS Foundation Trust (UCLH). It is funded by the Department of Health to provide diagnosis and care for patients with, or suspected to have, any form of human prion disease (Creutzfeldt-Jakob disease, CJD). The clinic is integrally linked with the MRC Prion Unit at the Institute of Neurology, a Postgraduate Research Institute of University College London. The NPC provides diagnosis and care for all forms of prion disease (inherited, iatrogenic, sporadic and variant CJD). We aim to review new patients within a week of referral. The NPC also plays a key role in facilitating research to promote early diagnosis and the development of potential therapies.

CJD patient support group:

National CJD Support Network

Web: <http://cjdsupport.net/>

The CJD Support Network is a patient support group providing help and support for people with all strains of Creutzfeldt-Jakob disease, their carers and concerned professionals. It also provides support for people who have been informed that they are at a higher risk of CJD through secondary transmission, ie blood transfusion or surgical instruments. The network:

- provides practical and emotional support to individuals affected by CJD and their families
- provides practical and emotional support for people who are informed that they are at a higher risk of secondary transmission CJD through a blood transfusion or surgical instruments
- supports families in financial need through caring grants
- links families with similar experiences of CJD, for mutual support
- runs a national helpline giving information on all forms of CJD

For enquiries related to non-standard incidents not covered by this guidance:

ACDP TSE Risk Management Sub Group

Email: acd@phe.gov.uk