

FORM 1: PROCEDURE LOOKBACK AND RISK ASSESSMENT

This form is for local use to collect the information needed conduct a risk assessment report of a new case of CJD or person at increased risk of CJD.

Instructions

1. Record the index patient details (please do not include patient name)
2. Record details of all invasive procedures carried out in the agreed lookback period
3. Risk assess each procedure for the CJD infectivity of the tissues involved
4. Clarify risk assessment of any procedures assessed as uncertain with the relevant clinicians
5. Assign a local reference so that the incident can be identified
6. Retain form as part of the incident record
7. **Return a copy of the form to: cjd@phe.gov.uk**

Index patient details

NCJDRSU number

HPZone number (if applicable)

Incident reference (To be assigned locally)	CJD status Choose an item.	CJD type Choose an item.	Lookback period Click here to enter text. (DD/MM/YYYY – DD/MM/YYYY)
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Results of procedure lookback

Procedure name	Procedure date (DD/MM/YYYY)	Hospital	Specialty	Relevant complications or techniques used*	CJD infectivity of tissues
Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Choose an item.
Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Choose an item.
Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Choose an item.
Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Choose an item.
Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Choose an item.
Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Choose an item.
Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Choose an item.
Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Choose an item.
Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Choose an item.
Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	Choose an item.

*For example, for some procedures the method or technique used may determine if high and/or medium infectivity tissues are involved (see TSE infection control guidelines).

Notes: Click here to enter text.

Form completed by: Click here to enter text. Date: Click here to enter text.

Field descriptions

Field	Description (Response format)
NCJDRSU number	Unique reference number assigned by the National CJD Research and Surveillance unit in Edinburgh
Incident reference	A locally assigned incident reference for identification purposes (free text)
CJD status	<p>The CJD status of the index patient is the classification of their diagnosis for symptomatic patients and their exposure to a risk of CJD for asymptomatic patients. Groups of patients at increased risk are described in more detail in table B of the guidance document “Public health action following a report of a new case of CJD or a person at increased risk of CJD”.</p> <p>(Either: Symptomatic – definite Symptomatic – probable Symptomatic – possible Symptomatic – suspected</p> <p>Or: Asymptomatic – genetic/inherited prion disease (see table B for definition) Asymptomatic – human growth hormone (see table B for definition) Asymptomatic – gonadotropin (see table B for definition) Asymptomatic – dura mater graft (see table B for definition) Asymptomatic – intradural surgery (see table B for definition) Asymptomatic – blood recipient (see table B for definition) Asymptomatic – blood donor (see table B for definition) Asymptomatic – other blood recipient (see table B for definition) Asymptomatic – plasma products (see table B for definition) Asymptomatic – highly transfused (see table B for definition) Asymptomatic – surgical (see table B for definition) Asymptomatic – other exposure (please specify)) (see table B for definition)</p>
CJD type	The type of CJD that the index patient has or is at increased risk of (sporadic, genetic, variant, iatrogenic, variant (iatrogenically acquired))
Lookback period	The agreed procedure lookback period. This is dependent on the CJD status of the index patient. (free text) (DD/MM/YYYY)
Procedure name	The name of the invasive procedure (free text)
Procedure date	The date the procedure took place (DD/MM/YYYY)
Hospital	Where the procedure took place (free text)
Specialty	The specialty of the procedure (free text)
Relevant complications or techniques used	Details of any relevant complications or techniques used. (free text)
CJD infectivity of tissues	The CJD infectivity of the tissues involved in the invasive procedure (high, medium, low, uncertain)
Notes	Any other relevant information to the risk assessment of the procedures and information regarding any missing notes etc. (free text)
Form completed by	The person(s) who completed the form (free text)
Date	The date the form was completed (DD/MM/YYYY)