Leicestershire Partnership NHS Trust

Transmissible Spongiform Encephalopathy (TSE) including Creutzfeldt-Jacob Disease (CJD) Variant CJD (VCJD) Policy.

This policy describes the process for managing patients with suspected Transmissible Spongiform Encephalopathy (TSE) including Creutzfeldt-Jacob Disease (CJD) variant CJD (VCJD) within Leicestershire Partnership NHS Trust,

Policy Reference Number: P120

Version Number: 6

Date Approved: 24th June 2026

Approving Group: Quality & Safety committee

Review Date: 1st December 2028

Expiry Date: 31st June 2029

Type of Policy Clinical

Keywords: Infection Prevention & Control, Transmissible Spongiform Encephalopathy, Creutzfeldt-Jacob Disease

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Summary and aim

The Aim of this policy is to give direction to staff within Leicestershire Partnership Trust (LPT) with regards to caring for patients with suspected Transmissible Spongiform Encephalopathy (TSE), including Creutzfeldt-Jacob disease (CJD) & Variant Creutzfeldt-Jacob Disease (VCJD).

The transmission risks & diagnosis of the disease are identified, including the necessary infection prevention & control precautions with the overall aim being to reduce the risk of transmission.

This policy sets out to ensure that all staff employed by LPT provide evidence-based care which is in accordance with the health & social care Act (2008) updated in (2015).

Target audience

This policy applies to all staff providing care to patients under the care of Leicestershire Partnership Trust (LPT) who are suspected or confirmed to have Transmissible Spongiform Encephalopathy (TSE) including Creutzfeldt-Jacob disease CJD & Variant Creutzfeldt-Jacob disease (VCJD).

Training

Infection Prevention & Control Level 1(Non-Clinical staff & clinical staff groups)

Infection Prevention & Control Level 2 (Clinical staff Groups)

IPC delivery of additional Infection specific training as may be required.

Key requirements

This policy is designed to provide trust wide guidance for staff on the process for the management of patients with suspected/confirmed TSE, CJD or VCJD infection who are under the care of LPT.

The key requirement of this policy is to ensure that patients with TSE, CJD or VCJD infection are safely managed within inpatient/outpatient areas to ensure that the situation is controlled & managed with minimal risk to other patients, staff & continues to maintain public safety.

Introduction and Purpose

The aim of this policy is to give direction to staff within LPT with regards to caring for patients with suspected Transmissible Spongiform Encephalopathy (TSE), including Creutzfeldt-Jacob Disease (CJD) and Variant Creutzfeldt-Jacob Disease (VCJD).

The transmission risks and diagnosis of the disease are identified, including the necessary infection, prevention & control precautions with the overall aim being to reduce the risk of transmission.

This policy sets out to ensure that all staff employed by LPT provide evidence-based care which is in accordance with the health & social care act (2008) updated (2015).

The guidance in this policy covers all healthcare settings within LPT

There is currently **no known cure** for TSE, CJD or VCJD nor is there currently any formal means of diagnosis except following the death of a patient. Therefore, it is imperative that staff are aware of the signs & symptoms of the disease and of the necessary precautions they need to take when TSE, CJD or VCJD is suspected.

Patients with TSE, CJD.VCJD **are not an infection risk to other patients or staff** and therefore will **not** require source isolation precautions**.**

This disease is thought to be caused by the build-up of an abnormal form of prion proteins that are found in the brain which can be transferred by medical equipment following certain procedures which are deemed to be high risk, **NONE** of these high-risk procedures are currently undertaken within LPT services.

TSE is a group of diseases that affects both humans and animals, it is thought to be caused by the build-up of an abnormal form of the naturally occurring 'Prion' protein in the brain.

CJD is a form of TSE and is a rare and fatal degenerative disease.

CJD can be classed as **Classical** or **Sporadic,** it can also be **generic** or a form of i**nherited** prion disease which are associated with mutation in the prion protein gene.

Rarer forms of human prion disease include acquired diseases such as iatrogenic CJD-Iatrogenic CJD is rare and occurs when CJD is transmitted as a result of medical or surgical exposures.

To reduce this risk precautionary measures have been taken to improve the standards of surgical instruments and endoscope decontamination.

VCJD is thought to be most likely acquired through ingestion of meat contaminated with bovine spongiform encephalopathy agent.

1.0 Management of patients with transmissible Spongiform Encephalopathy (TSE) including Creutzfeldt-Jacob Disease (CJD) & Variant Creutzfeldt-Jacob Disease (VCJD).

1.1 Diagnosis

Diagnosis is usually made on a clinical basis as there are currently no widely available laboratory tests for human TSE.

At present diagnosis can only be confirmed by examination of the brain tissue after death (Postmortem).

A brain biopsy may be used in investigating cases of suspected TSE but may not be definitive in establishing a diagnosis.

1.2 Treatment

There are currently no cures available, and any treatment given would be to alleviate any symptoms where possible.

1.3 Screening

There is currently no screening process available that can give a conclusive diagnosis.

1.4 Infection Prevention & Control measures

A patient with suspected TSE is **not** an infection risk, therefore any patient who has been clinically 'Provisionally' diagnosed with TSE does not require source isolation precautions.

Standard Infection Prevention and control precautions such that are applicable to **all patients at all times should be undertaken:**

- Effective hand hygiene before and after each patient contact with their environment is of paramount importance in reducing spread of all infections (Please refer to the LPT hand hygiene policy).
- Antibiotics must be prescribed according to the antibiotic guidance for primary care.
- Personal Protective Equipment (PPE) must be worn where there is a risk of exposure to blood or body fluids (Please refer to the LPT personal protective equipment in healthcare policy).
- Cleaning and decontamination of equipment must be undertaken as per the LPT cleaning and decontamination policy.

There have to date only been 4 cases of presumed person-person transmission of VCJD infection via blood transfusion reported within the United Kingdom (UK) since 2003 (3 clinical & 1 Asymptomatic) and a further probable VCJD infection via plasma products has been reported in a haemophiliac person.

Since 1997 when the theoretical risk of VCJD transmission through blood was first considered, the UK blood services have taken a number of precautionary measures to protect the blood supply and associated plasma products, these include:

- Blood components, plasma products, or tissues obtained from any person who later develops VCJD are withdrawn or recalled preventing their use.
- Since 1998 plasma for the manufacture of plasma products, such as clotting factors has been obtained from non-UK sources.
- Since 1998 synthetic (Recombinant) clotting factors for treatment of haemophilia has been provided to those under the age of 16 and for all patients in whom it is suitable since 2005.
- Since 1999 white blood cells (Which may carry a significant risk of transmitting VCJD have been removed in all blood used for transfusion a process known as leucodepletion.

- Since 2002 fresh frozen plasma for treating babies and young children born on or after 1st January 1996 has been obtained from the USA, in 2005 it is use was extended to all children up to the age of 16.
- Since 2004 individuals who have received a transfusion of blood components since January 1980 or are unsure if they have had a blood transfusion are excluded from donating blood or platelets.
- Since 2009 Cryoprecipitate a special cold-treated plasma preparation has been imported from the USA for children up to the age of 16.

Even though the risk of obtaining CJD through blood and body fluids is very low, samples from patients who are suspected of having or at an increased risk of CJD should be treated as potentially infectious and any samples sent to the laboratory should indicate that the patient from whom the sample is taken is suspected of having TSE, CJD or VCJD should this be the case.

When patients suspected of TSE, CJD or VCJD have certain procedures undertaken in theatres, including day surgery and endoscopy then the equipment used may need to be quarantined until a diagnosis can be made and disposed of if a positive diagnosis is made.

However, LPT do not currently support these services and therefore this is not permitted to LPT.

1.5 Movement and transport of patients

There are no infection prevention and control requirements to be implemented other than standard precautions that are required for all patients when patients are being moved from one area to another or transported in vehicles, including volunteer cars, private cars, or ambulance transportation.

1.6 Caring for patients within the community setting.

People should not be dissuaded from routine contact with patients with TSE, CJD or VCJD as they are not thought to present any risk through normal social or routine clinical contact.

No special measures over and above standard infection prevention and control measures are required for caring for patients with TSE, CJD or VCJD patients in the

community as it is unlikely that procedures will be adopted that will lead to contact with high or medium risk.

1.7 Deceased patients

After the patient has died, staff will need to contact the mortuary for the up-to date protocols and the following must be undertaken:

- The patient must be placed into a body bag prior to transporting to the mortuary.
- Normal procedures for bodies where there is a known infection risk must be followed.
- Embalming should be avoided in confirmed/suspected cases.

In all cases discuss with a consultant histopathologist regarding postmortem examinations, postmortems on diagnosed or suspected TSE patients are to be carried out at the Queen Medical centre (QMC) Nottingham.

Roles and Responsibilities

Roles and responsibilities including duties of relevant individuals and groups.

Lead Executive Director

Responsible for ensuring that this policy is carried out effectively and that patients who are suspected/confirmed as having TSE, CJD OR VCJD are manged effectively across the organisation.

Executive Management Board

Responsible for ensuring that this policy is carried out effectively and that hand hygiene is addressed and manged effectively across the organisation.

They will also communicate, disseminate, and ensure that directorates implement the policy and provide assurance through the trust quality governance framework.

Governance Group level 1 and 2

Responsible for ensuring that all relevant staff are aware of the Policy and adhere to the principles and guidance that is contained within it.

Policy Team

Responsible for ensuring that the policy is reviewed in accordance with identified timescales and implementation of monitoring and effectiveness has been planned, is reviewed by directorates and appropriate governance groups.

Policy Authors

Responsible for ensuring that the infection, prevention, and control team identify best learning and practice to inform this policy and update accordingly.

To ensure that this policy is reviewed in accordance with identified timescales and implementation of monitoring and effectiveness has been planned, is reviewed by the directorate, and appropriate governance group.

Operational leads

Responsible for ensuring the policy is implemented within their area and for ensuring that all staff who work within the area adhere to the principles of this policy at all times.

Staff

Each individual member of staff, substantive and temporary worker within the trust is responsible for complying with this policy. Clinical staff involved in the care of patients will ensure that they familiarise themselves with the content of the policy and work in accordance with this.

Staff will ensure that they provide support and education to the patient, carer, and family where appropriate.

They will also be a source of knowledge and skill for colleagues where appropriate as well as ensure that they remain up to date with training in line with competencies of their job roles.

Consent

Clinical staff must ensure that consent has been sought and obtained before any care, intervention or treatment described in this policy is delivered.

Appendix One: Definitions that apply to this policy.

Transmissible Spongiform Encephalopathy (TSE)	Transmissible Spongiform Encephalopathy (TSE) is a group of diseases that are caused by the build-up of an abnormal form of the naturally occurring prion protein in the brain.
Cretuzfeldt-Jacob disease (CJD)	Creuzfeldt-Jacob Disease (CJD) is a form of TSE
Variant Creutzfeldt-Jacob Disease (VCJD)	Variant Creutzfeldt-Jacob Disease (VCJD) is a **Prion disease** that was first described in 1996 in the United Kingdom, there is now strong scientific evidence that the agent responsible for the outbreak of prion disease in cow's **bovine spongiform encephalopathy** (BSE or Mad cow disease) is the same agent responsible for the outbreak of VCJD in humans.
Classical CJD	Classical CJD is a human prion disease, it is a neurodegenerative disorder with characteristic clinical and diagnostic features. This disease is rapidly progressive and always fatal, infection with this disease leads to death usually within 1 year of onset of illness.
Healthcare Acquired Infection (HCAI).	HCAI are infections that are acquired as a result of healthcare interventions.
Iatrogenic	Brought about by surgical or medical treatment

Infection	Invasion of the body by organisms causing disease
Prion	A small infectious particle composed of abnormally folded protein that causes progressive neurodegenerative conditions. These abnormally folded proteins do not multiply in the host organism that they infected, Instead, they affect the brain structure by acting as a template inducing proteins with normal folding to convert to the abnormal prion form.
Standard precautions	The precautions taken by all staff for all patients all of the time based on risks identified.

Appendix Two: Governance

Version control and summary of changes

Version number	Date	Description of key change
Version 1	May 2014	Review of national guidelines for policy relevant to LPT. Infection Prevention & Control advice pertaining to theatres, day surgery and endoscopy departments is currently provided by UHL-Therefore staff are directed to this team for advice pertaining to these services. Circulated for comments to relevant parties within LPT and outside organisations.
Version 2	July 2017	Clarification that no new national guidelines available, Policy updated in line with the latest LP template for policies. Information relating to UHL services removed as not relevant to LPT.
Version 3	November 2019	Clarification that no new guidelines available Policy updated in line with the latest LPT template for policies.
Version 4	December 2020	Clarification that no new guidelines available Policy updated in line with the latest LPT template for policies.
Version 5	August 2023	Clarification that no new guidelines available Policy updated in line with the latest LPT template for policies.
Version 6	May 2026	Clarification that no new guidelines available Policy updated in line with the latest LPT template for policies.

Responsibilities

Responsibility	Title
Executive Lead	*Group chief nurse*
Policy Author	*Head of Infection Prevention and Control*
Advisors	*Infection Prevention and Control Assurance Group.*
Policy Expert Group	

Governance

Governance Level	Name
Level 1 Assurance Oversight	*Quality & Safety committee*
Level 2 Delivery Group for policy approval and compliance monitoring	*Infection Prevention & Control Assurance Group.*

Compliance Measures

KPI (only need 1-2 KPI's per policy)	Where will this be reported and how often
100% of reported cases will be reviewed (Notification would only be received following a postmortem examination)	IPC assurance group as required by clinical case/incidence.

Training Requirements

Infection Prevention & Control Level 1 E-learning (non-clinical staff & clinical staff groups)

Infection Prevention & Control Level 2 E-learning (Clinical staff Groups)

Infection Prevention & control team delivery of additional training as is required.

References

Advisory Committee on Dangerous Pathogens-Spongiform Encephalopathy (1998) Revised and updated 2009

Control of Substances Hazardous to Health (COSHH) regulations (2002)

Department of health Creutzfeldt-Jacob Disease: Guidance for healthcare workers (2000)

Department of health Transmissible spongiform encephalopathy agents: Safe working and the prevention of infection: part 4 (2003, revised and updated 2015)

Department of health: The health and social care act code of practice for health and adult social care on the prevention of infections and related guidance (2008) updated 2015.

Health, and safety at work act (1974)

Management of health and safety at work regulations (MHSWR) (1999)

Department of health and social care: Infection prevention and control of Creutzfeldt-Jacob Disease (CJD) in healthcare and community settings part 4 (2003) updated (2021)

LPT Hand hygiene including bare below the elbows policy (2026)

LPT Management of a patient requiring source isolation precautions policy

(2024)

LPT Personal protective equipment for use in health care policy (2025)

LPT Cleaning and decontamination Policy (2025)

Medical devices agency: Devices bulletin, single use medical devices implications and consequences of reuse (MDA DB2006 04) (2006)

National Institute for Health and Clinical Excellence (NICE): Patients safety and reduction of risk of transmission of Creutzfeldt-Jacob Disease (CJD) via interventional procedures (2006)

NHS England: National infection prevention and control manual for England 14th April 2022 (updated 13th April 2026)

Public Health England (PHE) Patients at increased risk of Creutzfeldt-Jacob Disease Background information (2016)