

To: Neurologists/neuropathologists

29th August 2025

Dear Colleague,

DIAGNOSTICS SERVICES AND REPORTING OF CJD CASES AND SUSPECT CASES: ARRANGEMENTS FOR 2025-2026

This letter updates arrangements for Creutzfeldt-Jakob Disease (CJD) in the UK. It updates the 2004 CMO letter and subsequent 2016 public health reporting arrangements letter. This reflects the changes following the creation of the National CJD Diagnostic Advisory Service (NCJDAS) based in the University of Edinburgh and reorganising of surveillance services across the UK.

The UK CMOs remain committed to ensure appropriate diagnosis and surveillance are in place for the purpose of minimising the risk of spread of CJD in the UK population.

The responsibility for care and investigation of individual patients remains with the consultant responsible for that patient in consultation with the general practitioner. There will be continuing support for clinicians and pathologists dealing with suspected cases of CJD and related prion diseases available in the National Prion Clinic (NPC) in London and the NCJDAS based in the University of Edinburgh.

Details of the services available are available on the websites:

- NCJDAS: <https://cjd.ed.ac.uk/>
- NPC: <https://www.uclh.nhs.uk/our-services/find-service/neurology-and-neurosurgery/national-prion-clinic>

Clinicians across the UK can access these services. To access these services:

1. Clinicians are asked to continue to **refer to both the NCJDAS and NPC** using the referral form available on the website <https://cjd.ed.ac.uk/>. The two units will liaise to ensure both are aware of all referrals:
 - NCJDAS: loth.securecjd@nhs.scot,
 - NPC: uclh.prion.help@nhs.net
2. Expert advice on the **clinical diagnosis** of CJD and related prion diseases will be provided by NCJDAS and NPC. Investigations to support a clinical diagnosis will be available, including:
 - CSF RT-QuIC testing via the national CSF RT-QuIC Laboratory, based in Edinburgh. Clinicians are to make requests to this directly, using the CSF request form available on the website (<https://cjd.ed.ac.uk/csf>) and the subsequent results will be shared with the NPC.
 - *PRNP* gene sequencing conducted by the NPC in London
3. An NHS commissioned provision for **specialist nursing care and advice** is available through the integrated services of NPC in London, and/or nurses in NHS Lothian in Edinburgh. Together, these services support patients with suspected or confirmed prion disease and their families across the UK. Access to specialist nursing teams should be initiated after completion of a diagnostic process involving the NPC and NCJDAS, to ensure clarity for patients and their families, appropriate triage and resource allocation.

Clinicians seeking to request care support for CJD patients may contact the services using the following details:

- NCJDAS: loth.specialistncjd@nhs.scot
- NPC: uclh.prion.help@nhs.net

Given the importance of identifying new cases, it is also the responsibility of the clinician, Trust or Health Board to **report suspected cases and deaths**. Please ensure the following are notified:

- Your Health Board or Trust's **infection control team**, who can identify contact details of the local health protection/public health team if necessary
- Your **local health protection or public health team** who will then work with the relevant trusts, hospitals or health boards to investigate and manage any public risk.

The reporting arrangements across the UK are as follows:

	How to report CJD cases for public health and surveillance	Website or contact details
England	All suspected or confirmed cases of CJD should be reported by notification through NOIDS, the Notification of Infectious Diseases.	Link to NOIDS: https://www.gov.uk/guidance/report-a-notifiable-disease
Northern Ireland	All suspected cases of CJD should be reported to the Health Protection Service in PHA by email (without including patient details), requesting a call back. A member of the health protection team will then contact the clinician to collect information.	Email: PHA.DutyRoom@hscni.net Phone: 0300 555 0119
Scotland	All confirmed probable and possible cases of CJD to be reported to the local NHS board Health Protection Team (HPT) in their Public Health Department requesting a call back. A member of the HPT will then contact the clinician to collect information. Confirmed, probable and possible cases will be reported to PHS by Health Protection Teams and by the NCJDAS.	Link to contact details of the Health Protection Teams in Scotland: https://publichealthscotland.scot/contact-us/general-enquiries/health-protection-team-contacts/
Wales	Notify the Public Health Wales Health Protection Team of any possible, probable or confirmed cases of CJD by emailing the Public Health Wales Health Protection Team.	Email: aware@wales.nhs.uk Phone: 0300 00 300 32

Yours sincerely,

Professor Chris Whitty, Chief Medical Officer, England

Professor Isabel Oliver, Chief Medical Officer, Wales

Professor Sir Michael McBride, Chief Medical Officer, Northern Ireland

Professor Sir Gregor Smith, Chief Medical Officer, Scotland