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Dear Colleague,

REPORTING CJD CASES AND SUSPECT CASES TO LOCAL PUBLIC HEALTH TEAMS

Public health teams should be informed about all cases and suspect cases of Creutzfeldt-Jakob Disease (CJD). This includes those cases that do not fulfil internationally accepted diagnostic criteria (see <http://www.cjd.ed.ac.uk/surveillance>), but where the diagnosis of CJD is being actively considered. This is necessary as patients with CJD may have had surgery and a local response may be required to help prevent any possible spread of CJD between people.

To carry out this important public health action, when you refer cases and suspect cases to the National CJD Research & Surveillance Unit (NCJDRSU), **please inform your local HEALTH PROTECTION / PUBLIC HEALTH TEAM, if you have not already done so. You may use the reporting form overleaf to do this. Your local INFECTION CONTROL TEAM should also be informed.** The public health team will then review case medical notes and work with staff in the relevant trusts and health boards to investigate and manage any public health risk. The public health team may also contact you directly if they have questions regarding the case.

All cases of suspect CJD should continue to be notified to the National CJD Research & Surveillance Unit (NCJDRSU) in Edinburgh and the National Prion Clinic (NPC) in London in accordance with the system outlined in the Chief Medical Officer's letter of July 2004.

With many thanks for your help.

Yours faithfully,



Professor Colin Smith
Director (NCJDRSU)

PUBLIC HEALTH CJD REPORTING FORM January 2019

To the reporting clinician: please complete the following information for reporting cases and suspect cases of CJD to your local health protection/public health team. They may then use this information to help them follow-up your patient's medical records. The health protection/public health team may contact you for more information if needed.

Name of reporting clinician															
Contact details															
Name of lead consultant in health protection/public health															
Contact details															
Name of patient															
Date of birth															
Unique Patient NCJDRSU Number															
Current/last known address of patient															
Name and details of GP of patient															
This patient has been diagnosed with (tick)	The diagnostic certainty is (tick)														
<table style="width: 100%;"> <tr> <td style="width: 30%;">CJD</td> <td style="width: 10%;"><input type="checkbox"/></td> </tr> <tr> <td>Variant CJD</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Other (specify)</td> <td><input type="checkbox"/></td> </tr> </table>	CJD	<input type="checkbox"/>	Variant CJD	<input type="checkbox"/>	Other (specify)	<input type="checkbox"/>	<table style="width: 100%;"> <tr> <td style="width: 30%;">Confirmed</td> <td style="width: 10%;"><input type="checkbox"/></td> </tr> <tr> <td>Probable</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Possible</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Other (specify)</td> <td><input type="checkbox"/></td> </tr> </table>	Confirmed	<input type="checkbox"/>	Probable	<input type="checkbox"/>	Possible	<input type="checkbox"/>	Other (specify)	<input type="checkbox"/>
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Possible	<input type="checkbox"/>														
Other (specify)	<input type="checkbox"/>														
Onset date															
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Comment															
Signature of reporting doctor Date															

To the local health protection/public health team: guidance on the public health actions to be taken following a report of a new case of CJD is available at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/474338/CJD_public_health_action_new_case_301015.pdf