Public Health England

Health Protection Report
weekly report

Infection report

Volume 9 Number 5 Published on: 13 February 2015

Creutzfeldt-Jakob disease (CJD) biannual update (February 2015)

This six-monthly report provides an update on the enhanced surveillance of potential iatrogenic (healthcare-acquired) exposures to Creutzfeldt-Jakob Disease (CJD). The data is correct as at 31st December 2014. For numbers of CJD case reports, readers should consult data provided by the National CJD Research and Surveillance Unit (NCJDRSU, http://www.cjd.ed.ac.uk/data.html).

Monitoring of patients 'at increased risk' of CJD

Individuals who have been identified as at increased risk of CJD as a consequence of their medical care are informed of their exposure and asked to follow public health precautions to avoid potentially transmitting the infection to others. They are also followed-up to help determine the risks of CJD transmission to patients through different routes and to ascertain whether any people who may have been exposed to increased CJD risks go on to develop CJD.

Public Health follow-up activities include clinical monitoring, General Practitioner (GP) updates, and post mortem investigations to determine whether asymptomatic individuals in these groups have been infected with the CJD agent. Some individuals also provide blood or tissue specimens for research purposes. A number of different organisations are involved in these activities: Public Health England (PHE) formerly the Health Protection Agency (HPA), Health Protection Scotland (HPS), UCL Institute of Child Health/Great Ormond Street Hospital (ICH), NHS Blood and Transplant (NHSBT), National CJD Research and Surveillance Unit (NCJDRSU), National Prion Clinic (NPC), and the UK Haemophilia Centre Doctors' Organisation (UKHCDO).

The PHE CJD Section coordinates the collation of data on individuals identified as at increased risk of CJD, and who have been informed of this. These individuals are followed up through public health monitoring and research activities by different organisations.

The PHE CJD Section currently holds data on the following groups of ‘at risk' patients:

- recipients of blood components from donors who subsequently developed vCJD
- blood donors to individuals who later developed vCJD
- other recipients of blood components from these blood donors
- recipients of certain plasma products between 1990 and 2001 (non-bleeding disorder patients)
- certain surgical contacts of patients diagnosed with CJD
- highly transfused recipients.

Data on the following risk groups are not held by PHE, but are held by other organisations:

- bleeding disorder patients who received plasma products between 1990 and 2001 (UKHCDO)
- recipients of human derived growth hormone before 1985 (ICH)
- patients who could have received a dura mater graft before August 1992 (data not currently collected)
- people who have been treated with gonadotrophin sourced from humans before 1973 (data not currently collected)
- family risk of genetic prion disease (NPC).

The data from the UKHCDO are likely to be a slight underestimate of the true number of ‘at risk' patients with bleeding disorders who received UK-sourced clotting factors, as there was incomplete reporting of identified ‘at risk' patients by haemophilia centres to the UKHCDO database. Notified ‘at risk' patients are given the option of removing their details from the UKHCDO database, and are then removed from the ‘at risk' totals.

The data on ‘at risk' patients who received human-derived human growth hormone held by the ICH is also a slight underestimate of the total as a small number of these patients are not included in the ICH follow-up.

Summary of all ‘at risk’ groups on which data are collected (as at 31 December 2014)

'At risk' Group	Identified as 'at risk'	Number notified as being 'at risk'		Cases	Asymptomatic infections [a]
		All	Alive		
Recipients of blood from donors who later developed vCJD	67	27	14	3	1
Blood donors to individuals who later developed vCJD	112	108	104	0	0
Other recipients of blood components from these donors	34	32[b]	19[b]	0	0
Plasma product recipients (non-bleeding disorders) who received UK sourced plasma products 1990-2001 [c]	2	2	2	0	0
Certain surgical contacts of patients diagnosed with CJD	196	163 [d]	139[e]	0	0
Highly transfused recipients [f]	3	3	3	0	0
Total for ‘at risk’ groups where PHE holds data	**414**	**335[g]**	**281[g]**	**3**	**1**
Patients with bleeding disorders who received UK sourced plasma products 1990-2001 [h]	4,016	3,540 [i]	3,151 [i]	0	1
Recipients of human derived growth hormone [h]	1,883	1,883	1,501	77	0
Total for all ‘at risk’ groups	**6,313**	**>5,758**	**>4,933**	**80**	**2**

a. An asymptomatic infection is when an individual does not exhibit any of the signs and symptoms of CJD in life but abnormal prion protein indicative of CJD infection has been found in tissue obtained at post mortem.

b. One patient was notified by proxy.

c. An additional 8 people originally identified are no longer considered to be at increased risk and have been denotified where appropriate

d. even of these were notified by proxy.

e. Three of these were notified by proxy.

f. An additional 8 people originally identified are no longer considered to be at increased risk and have been denotified where appropriate

g. Includes patients who were notified by proxy.

h. These are minimum figures. Central reporting for bleeding disorder patients is incomplete, and a small number of patients have opted out of the central UKHCDO database. A small number of ‘at risk’ growth hormone recipients are not included in the Institute of Child Health study. Not all of the ‘at risk’ growth hormone recipients have been notified. There is no central record of who has been informed.

i. These are the minimum number of people notified based on those patients who were seen for care after the notification exercise. It is likely that many more of the at risk patients received their notification letter but as they were not subsequently recorded as being seen for care this cannot be confirmed.