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INFECTED BLOOD INQUIRY

EXHIBIT WITN7088006

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UK Health Security Agency (https://www.gov.uk/government/organisations/uk-health-security-agency)

Research and analysis

Creutzfeldt-Jakob disease (CJD) update (data to end of December 2021)

Updated 21 June 2022

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This publication is available at https://www.gov.uk/government/publications/creutzfeldt-jakob-disease-cjd-surveillance-biannual-updates/creutzfeldt-jakob-disease-cjd-update-data-to-end-of-december-2021

This 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 31 December 2021. For numbers of CJD case reports, readers should consult data provided by the National CJD Research and Surveillance Unit (http://www.cjd.ed.ac.uk/surveillance/data-and-reports) (NCJDRSU).

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 mortality monitoring, and in some cases, post mortem investigations to determine whether asymptomatic individuals have been infected with the CJD agent. A number of different organisations are involved in these activities: UK Health Security Agency (UKHSA), Public Health Scotland (PHS), UCL Institute of Child Health/Great Ormond Street Hospital (ICH), NHS Blood and Transplant (NHSBT), NCJDRSU, National Prion Clinic (NPC), and the UK Haemophilia Centre Doctors' Organisation (UKHCDO).

The UKHSA 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 UKHSA CJD Section currently holds data on the following groups of patients who have been identified as 'at increased risk' of CJD:

- 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 UKHSA, 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)
- individuals treated with gonadotrophin sourced from humans before 1973 (data not currently collected)
- family risk of genetic prion disease (NPC)

The data from the UKHCDO is likely to be a slight underestimate of the true number of patients with bleeding disorders who received UK-sourced clotting factors (1990 to 2001), as there was incomplete reporting of identified patients by haemophilia centres to the UKHCDO database. Notified patients are given the option of removing their details from the UKHCDO database, and are then removed from the 'at increased risk' totals.

The data on patients who received human-derived growth hormone held by the ICH (until the end of December 2021) is also a slight underestimate of the total as a small number of these patients are not included in the ICH follow-up.

Data concerning recipients of human-derived grown hormone before 1985 was transferred to UKHSA at the start of 2022.

Summary of all 'at increased risk' groups on which data is collected (data correct as at 31 December 2021)

'At increased risk' group	Identified as 'at increased risk'	Total notified	Total notified and alive	Cases	Asymptomatic infections *
Recipients of blood from donors who later developed vCJD	67	27	13	3	1
Blood donors to individuals who later developed vCJD	112	108	98	0	0

'At increased risk' group	Identified as 'at increased risk'	Total notified	Total notified and alive	Cases	Asymptomatic infections *
Other recipients of blood components from these donors	34	32	11	0	0
Plasma product recipients (non-bleeding disorders) who received UK sourced plasma products 1990 to 2001	2	2	2	0	0
Certain surgical contacts of patients diagnosed with CJD	339	284	220	0	0
Highly transfused recipients	3	3	1	0	0
Total for 'at increased risk' groups where UKHSA holds data	**557**	**456**	**345**	**3**	**1**
Patients with bleeding disorders who received UK sourced plasma products 1980 to 2001 **, ‡	3,637	3,281 †	2635	0	1
Recipients of human derived growth hormone **	1,883	1,883	1,383	82	0
Total for all 'at increased risk' groups	**6,077**	**5,620**	**4,363**	**85**	**2**

*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.

**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 increased risk' growth hormone recipients are not included in the Institute of Child Health study. Not all of the 'at increased risk' growth hormone recipients have been notified. There is no central record of who has been informed.

†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 increased risk' patients received their notification letter but as they were not subsequently recorded as being seen for care this cannot be confirmed.

‡Including a small proportion of individuals known to have been treated with UK plasma products 1980 to 2001, and presumed to have also been treated 1990 to 2001.

Current status of 'at increased risk' groups (data correct as at 31 December 2021)

Age, sex and notification status of 'at increased risk' patient groups	Recipients	Donors	Other recipients	Highly transfused	Plasma bleeding	Plas non blee
Current status						
Alive	13	100	11	1	2,672	2
Dead	54	12	23	2	875	0
Total	67	112	34	3	3,637	2
Notification status						
Notified	27	108	32	3	3,281	2
Alive and notified	13	98	11	1	2,635	2

Age, sex and notification status of 'at increased risk' patient groups	Recipients	Donors	Other recipients	Highly transfused	Plasma bleeding	Plas non blee
Genotype						
MM	11	–	–	–	5	–
MV	8	–	–	–	4	–
VV	–	–	–	–	1	–
Not known	48	112	34	3	3,627	2
Sex						
Male*	19	53	16	1	3,093	2
Female*	20	58	18	2	544	0
Not known*	28	1	0	0	0	0
Current age band						
0 to 19	0	0	1	0	0	0
20 to 39	0	0	1	1	814	0
40 to 59	5	35	5	0	1,152	2
60 to 79	4	57	4	0	688	0
80+	4	8	0	0	108	0

*Sex is provided for all patients (alive and dead) except for recipients of human derived growth hormone for which sex is provided for those still alive only.

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