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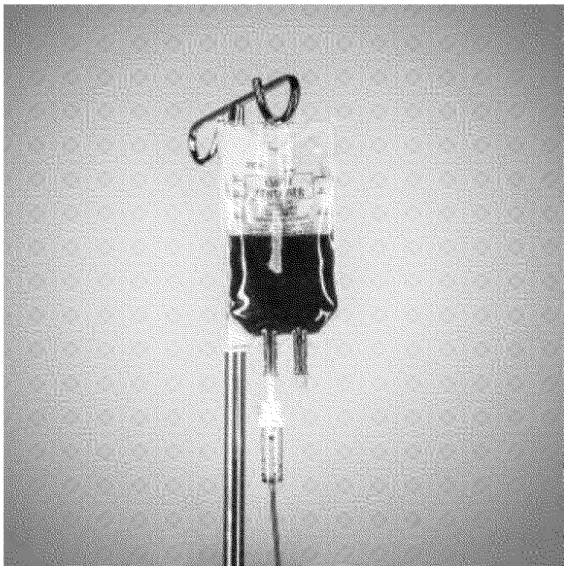
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The Transfusion Medicine Epidemiology Review (TMER)

The Transfusion Medicine Epidemiology Review (TMER)



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The Transfusion Medicine Epidemiology Review (TMER) is a collaborative project between the UK National CJD Research & Surveillance Unit (NCJDRSU) and the UK Blood Services. The main purpose is to investigate whether there is any evidence that Creutzfeldt-Jakob disease (CJD) or variant Creutzfeldt-Jakob disease (vCJD) may have been transmitted via the blood supply.

METHODS

CJD/vCJD cases (definite and probables) are notified to the UK Blood Services by the National CJD Research & Surveillance Unit. Donation records are checked and all components traced through hospital records. Details of all identified recipients are forwarded to the National CJD Research & Surveillance Unit for subsequent checking.

In the reverse procedure, patients with CJD/vCJD reported to have received blood transfusions are traced through hospital records and relevant blood donors identified. The identity of donors is notified to the NCJDRSU for subsequent checking.

RESULTS (data to 21.06.21)

VARIANT CJD

Thirty-one vCJD cases were reported to have been blood donors. Four additional cases who were not reported to have been blood donors were found to be registered with UKBTS. One of these cases was found to have been a blood donor while the other three cases were registered as donors but never made any donations. Twenty-four of the cases have been traced at blood centres including the four additional cases mentioned above. Components from 18 of these individuals were actually issued to hospitals. It has been established that 67 components were transfused to named recipients (53 dead, 14 alive).

Four instances of probable transfusion transmitted infection have been identified. The first recipient (Case 1) developed symptoms of vCJD 6½ years after receiving a transfusion of red cells donated 3½ years before the donor (Donor 1) developed symptoms of vCJD. The second recipient (Case 2) died from a non-neurological disorder 5 years after receiving blood from a donor (Donor 2) who subsequently developed vCJD; protease-resistant prion protein (PrPres) was detected in the spleen but not in the brain. This is the first recorded case in the UK of

autopsy detection of presumed pre- or sub-clinical vCJD infection. The third recipient (Case 3) developed symptoms of vCJD 7 years, 10 months after receiving a transfusion of red cells donated about 21 months before the donor (Donor 3) developed symptoms of vCJD. The fourth recipient (Case 4) who also received a transfusion from the same donor as Case 3, developed symptoms of vCJD 8 years, 4 months after receiving a transfusion of red cells donated about 17 months before this donor (Donor 3) developed symptoms of vCJD. (see relevant publications below).

These findings strongly suggest that vCJD may be transmitted via blood transfusion. The identification of a third case of vCJD in this small cohort of known recipients of blood from persons incubating vCJD establishes beyond reasonable doubt that blood transfusion is a transmission route.







In the reverse study, 15 vCJD cases were reported to have received blood transfusions in the past. A further case received a blood transfusion after onset of illness. This case is excluded from the figures quoted. Checks revealed that of these 15 cases, one was not transfused, 4 had transfusions which pre-dated available records (pre 1980), and 10 had records of transfusion which could be traced (see vCJD cases who received blood transfusion(s) in the past below). These 10 had received 209 donor exposures (with one patient given 103 components), which have been traced to 192 named donors (two of whom had vCJD as described above).

OTHER FORMS OF CJD

A total of 391 blood transfusion recipients have been identified as having received blood from donors who were later diagnosed with non-variant CJD (sporadic or genetic) forms of CJD. Of these recipients, 198 are known to have died; there is no evidence that their deaths were related to CJD.

In the reverse study, 292 blood donors were identified whose blood donations had been transfused to patients later diagnosed with sporadic CJD. Eleven of these donors have died and there is no evidence that their deaths were related to CJD.

Further data from the study are shown below. Any enquiries relating to this project can be directed to Jan Mackenzie at jan.mackenzie@GRO-C

-  [vCJD Donor Summary.pdf](#)
-  [Use of Blood Donations from vCJD cases.pdf](#)
-  [Fate of recipients of labile blood components.pdf](#)
-  [vCJD Cases who received blood transfusion\(s\) in the past.pdf](#)
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vCJD DONOR SUMMARY

Number of vCJD cases in the UK ¹	178
Number who were eligible to donate (ie aged 17 and over)	168
Number reported by relatives to have been blood donors	31
Number of cases where donor records have been traced	24 ²
Number of cases from whom components were actually issued	18
Number of recipients identified from 18 cases where recipient and component information is available	67

¹Two non-UK cases not included in the above table had resided in the UK and were reported to have been blood donors while residing in the UK. Donor records were traced in the first but no issues were made. Donor records were traced in the second and it was established that components were issued but information on issues predated available records.

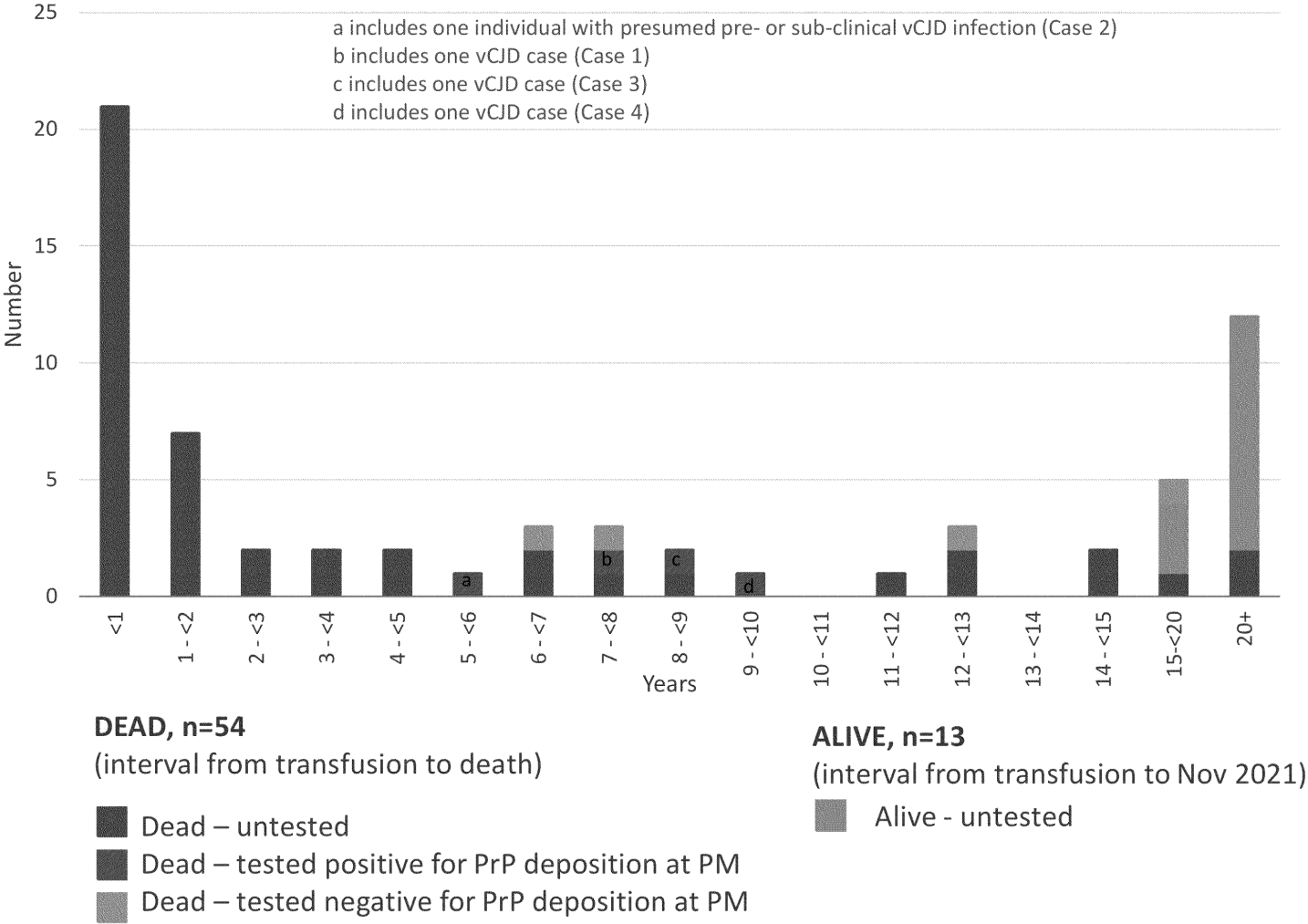
²Donor records were traced on four where the relatives had reported the case not to be a donor.

USE OF BLOOD DONATIONS FROM vCJD CASES

TRANSFUSED:	Red cells	27
	Leucodepleted red cells	25
	Buffy-coat reduced red cells	2
	Fresh frozen plasma	3
	Fresh frozen plasma (leucodepleted)	2
	Whole blood	2
	Cryo-depleted plasma	1
	Cryoprecipitate	1
	Platelets (pooled)	2
	Platelets (pooled, leucodepleted)	2

In addition, 11 vCJD donors (including one non-UK case who donated while residing in the UK) contributed plasma to 25 plasma pools identified by UK fractionators (BPL & PFC) as having been used for the manufacture of plasma products prior to 1999.

RECIPIENTS OF LABILE BLOOD COMPONENTS DONATED BY vCJD CASES (n=67)



vCJD CASES WHO RECEIVED BLOOD TRANSFUSION(S) IN THE PAST

Recipient	Transfusion Episode	Number of donor exposures	Interval from transfusion to onset of illness
1	1	38	4 years, 9 months
1	2	65	4 years, 6 months
2	1	2	15 years, 11 months
2	2	3	6 years, 3 months
3	1	4	5 years, 4 months
4	1	5	8 months ¹
5 (Case 1)	1	5 ²	6 years, 6 months
6 (Case 3)	1	56 ³	7 years, 10 months
7	1	2	13 years, 11 months
8	1	4	16 years, 9 months
9 (Case 4)	1	21 ³	8 years, 4 months
9 (Case 4)	2	2	7 years, 8 months
10	1	2	5 years, 11 months

¹timing of clinical illness excludes blood transfusion as the source of infection in this recipient.

²one donor developed vCJD (Donor 1 referred to in Results section)

³one donor developed vCJD (Donor 3 referred to in Results section who donated to both Case 3 and Case 4)

RELEVANT PUBLICATIONS

- Llewelyn CA, Hewitt PE, Knight RSG, Amar K, Cousens S, Mackenzie J, Will RG. Possible transmission of variant Creutzfeldt-Jakob disease by blood transfusion. *Lancet* 2004; 363: 417-421.
- Peden AH, Head MW, Ritchie DL, Bell JE, Ironside JW. Preclinical vCJD after blood transfusion in a *PRNP* codon 129 heterozygous patient. *Lancet* 2004; 364: 527-529.
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- Gillies M, Chohan G, Llewelyn CA, Mackenzie J, Ward HJT, Hewitt PE, Will RG. A retrospective case note review of deceased recipients of vCJD-implicated blood transfusions. *Vox Sanguinis* 2009; 97: 211-218.
- Ward HJT, Mackenzie JM, Llewelyn CA, Knight RSG, Hewitt PE, Connor N, Molesworth A, Will RG. Variant Creutzfeldt-Jakob disease and exposure to fractionated products. *Vox Sanguinis* 2009; 97: 207-210.
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- Davidson LRR, Llewelyn CA, Mackenzie JM, Hewitt PE, Will RG. Variant CJD and blood transfusion: are there additional cases? *Vox Sanguinis* 2014; 107(3): 220-225.
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- Checchi M, Hewitt P, Bennett P, Ward HJT, Will RG, Mackenzie JM, Sinka K. Ten-year follow-up of two cohorts with an increased risk of variant CJD: donors to individuals who later developed variant CJD and other recipients of these at-risk donors. *Vox Sanguinis* 2016; 111: 325-332.
- Urwin P, Thanigaikumar K, Ironside JW, Molesworth A, Knight RS, Hewitt PE, Llewelyn C, Mackenzie J, Will RG. Sporadic Creutzfeldt-Jakob disease in 2 plasma product recipients, United Kingdom. *Emerg Infect Dis* 2017; 23(6): 893-897.
- Mackenzie JM, Turner M, Morris K, Field S, Molesworth AM, Pal S, Will RG, Llewelyn CA, Hewitt PE. Accuracy of a history of blood donation from surrogate witnesses: data from the UK TMER Study. *Vox Sanguinis* 2018; 113(5): 489-491.



General Data Protection Regulation (GDPR)

The Transfusion Medicine Epidemiology Review (TMER)

How we use your information

Updated 3rd October 2018

Reviewed 18th June 2020

Updated 10th August 2020

The Transfusion Medicine Epidemiology Review (TMER) is a collaborative public health surveillance project between the UK National CJD Research & Surveillance Unit (NCJDRSU), NHS Blood and Transplant (NHSBT) and the remaining UK Blood Services. The main purpose is to investigate evidence that Creutzfeldt-Jakob disease (CJD) and variant Creutzfeldt-Jakob disease (vCJD) may be transmitted via blood and help prevent disease spread. We share the minimum amount of personally identifiable information on CJD cases that is necessary, with the UK Blood services, who then use this to check against their records and identify individuals who have received or donated blood components from/to cases of CJD. Recipient and donor details (name, date of birth, address, NHS number, study number) are also shared with NHS Digital services in order to flag recipients and donors for the purpose of obtaining details on date, location and cause of death when a recipient or donor dies. Data are not always available for every field requested but, as a minimum, name and date of birth are a mandatory requirement.

The nature of this non-research project means we use personal identifiable information about individuals without their explicit consent. We have special permission to do this under Section 251 of the NHS Act 2006 and Health Service (Control of Patient Information) Regulations 2002 for England and Wales, and from the Public Benefit and Privacy Panel (PBPP) for Health and Social Care for Scotland.

We know how important it is to protect the privacy of individuals we hold personal identifying information on and as such we will:

- only ask for what we need
- make sure nobody has access to it who shouldn't
- only keep it for as long as we need to
- not make it available for commercial use (such as marketing)
- only use this information as the law allows
- carefully protect this information at all times
- provide training to staff who need to use personal identifying data to do their job
- only share this information as the law allows

- respond appropriately if personal information is not used or protected properly

Our staff are trained to treat personal information in the strictest confidence, in compliance with the General Data Protection Regulation (GDPR) and the NHS Caldicott principles and have a duty to maintain confidentiality. They undergo relevant Information Governance (IG) training and will only be allowed to deal with personal information if their IG training certificates are kept up to date. Any deliberate or negligent breaches of this policy are disciplinary offences.

Contact for further information

The NCJDRSU is the data controller under this privacy notice. If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) at <https://ico.org.uk/>.

Data Protection Officer contact information:

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General information about the legal basis of processing personal identifiable information by the NCJDRSU, including your rights, is available at http://www.cjd.ed.ac.uk/privacy_notice