CHIP – Care and Health Information Portfolio

DH Department of Health

Policy Statement

Variant Creutzfeldt-Jakob Disease (vCJD)

Created By :	Peter Jones	Created Date :	23/02/2000
Type :	Ministerial	Lead Minister	Ms Y Cooper
Related SofS Task Force :	All Priorities	Who should see this ? :	● DH High Level ○ DH Intranet (All Staff) ○ GSI (All Government Departments)

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Document Author :	Alan Harvey Peter Jones Philippa Edwards		
Lead Official :	Alan Harvey Ext GRO-C	Branch :.	PH6.1
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Policy Commitment (*If any*)

NONE

Topical Issues

1. Number of variant Creutzfeldt-Jakob Disease (vCJD) cases (figures published on first Monday of each month)

2. Prevention of transmission

A. Animals

i. Food safety - FSA lead, but DH has clear 'watching brief' role

a. bovine products - particular concerns at present over growing BSE epidemic in continental Europe

b. sheepmeat - MAFF are contingency planning over what to do if BSE is found in national flock. DH are represented on the contingency planning working group. Consultation exercise expected over the plans by March/April 2001

ii Environmental - no special concerns at present

B. Humans

iii. Iatrogenic (through medical interventions)

a. safety of blood and blood products - SEAC will be considering a number of blood-related issues at their forthcoming meeting on 28 February 2001 eg safety of fresh frozen plasma. Another key issue is handling requests for information from haemophiliacs who have received blood products which contain blood derived from a donor who went on to develop vCJD.

b. re-use of surgical instruments

The Department announced on 4 January 2001 a major 'performance managed' initiative to raise decontamination standards for surgical instruments, seen as key by SEAC to minimising risk of vCJD person-to-person transmission (first line of attack). Also the introduction of single-use tonsillectomy kits, as pilot for possible further use of single use instruments in due course (second line of attack).

c. organ and tissue transplants

A theoretical risk of vCJD transmission exists, but clearly addressing the immediate clinical need here would be paramount.

3. Surveillance and prevalence

i. Retrospective anonymous studies to look for abnormal prion protein in appendices and tonsils of asymptomatic individuals are underway and will run until the end of 2002. No positive results on 3,000 samples tested so far, but this should not be taken as an "all clear". In addition, prospective study of some 2,000 fresh tonsils is being undertaken by London Prion Unit. The first 1,000 samples have been collected and are now being analysed by Professor Collinge's team.

ii. Statistically significant rising trend in numbers of vCJD cases (of around 20-30% per annum to date) identified mid July 2000. Analysis by PHLS statisticians of most recent data (including up to Q3 2000) confirms this trend. Speculation that recent confirmation of first elderly case (74 year old) of vCJD may have implications for raising upper end of range-of-number predictions. Analyses still awaited from professor Anderson's Imperial College Group. Too early to predict ultimate size of epidemic.

iii. Apparent cluster of 5 cases in Leicestershire under investigation. Working with CDSC Colindale, PHLS, CJD Surveillance Unit, representatives from Local Public Health and Health care, to put in place a more systematic follow up and investigation of all reported cases of vCJD including potentially linked cases or alleged 'clusters'. Likely cause seen as being beef/beef products sold by meat retailers before current Specified Risk Material controls were introduced (November 1989) but we cannot yet be sure.

4. Care and compensation for patients and families (see below)

Government announced interim payments of £25,000 per family in February 2000

Key Facts

1. Disease is invariably fatal; patients develop physical and psychiatric symptoms which increase in severity until dementia and death supervene.

2. There are now 94 known definite and probable cases of vCJD in the UK, of which 8 are still alive.

In addition, 3 cases in France, 1 in Republic of Ireland. Oldest patient aged 74 ,youngest age of onset = 12

3. Disease caused by exposure to similar agent as causes BSE in cattle but route of human exposure not known.

4. Lengthy incubation period (possibly up to 20 years or more) so impossible to tell what long

term outcome might be, major epidemic cannot be ruled out.

5. Clinical presentation varies, definite diagnosis can usually only be confirmed in most cases by brain examination after death (takes about 6 weeks); either tonsil biopsy or magnetic resonance imaging of the brain (MRI scanning) can be used to help diagnose 'probable' cases of vCJD.

6. Following an announcement by Nick Brown on 26 October 2000, a specialist nurse and social worker are being appointed to support the national care co-ordinator at the CJD Surveillance Unit. The Government is making £1 million available immediately to pay for care packages.

7. In addition, a Managed Clinical Network is being established to provide clincial and practical advice to those taking on responsibility for the care of patients with vCJD for the first time, enabling them to develop structured care packages.

8. Ministers have decided that an interim payment of £25,000 should be made to the families of victims of vCJD in recognition of the suffering and expense incurred.

9. Comprehensive human health research strategy launched November 1996 and further expanded since. Government funding allocated for TSE research for 1999/2000 around £30 million. Of this DH has allocated about £4 million.

10. £70k grant per year (over 3 years from 1999/2000) to Alzheimer's Disease Society (ADS) for CJD Support Network for case co-ordination initiative; Human BSE Foundation awarded grant of £23K in 1999-200 to develop the organisation and £29k in 2000-2001. European Parliament have also voted funds for support of patients and families.

11. Guidance on caring for vCJD victims was issued to social services professionals in 1998 by the Association of Directors of Social services and new guidance to health workers was issued by the Department of Health in August 2000

12. £200m to modernise NHS decontamination facilities announced 4 January 2001. On same date the introduction of single-use instruments for tonsillectomy during 2001, at an extimated cost of some £25m, was announced.

Bull Points

1. CJD surveillance unit (CJDSU) set up 1990; the unit identified vCJD from only 10 cases in March 1996; continues to monitor all cases and analyse data. Care co-ordinator appointed based at CJD Surveillance Unit in early 2000 to provide source of expertise/advice to professionals & carers. Decision in October 2000 to add a specialist nurse and social worker to provide further support. £1m to be made available straightaway to pay for care packages.

2. Comprehensive research programme launched 1996, monitored by RAG and Funders' group and ultimately by the "high level committee" chaired by the Head of the Civil Service.

3. The Government relies on Spongiform Encephalopathy Advisory Committee (SEAC) for independent scientific advice on all matters concerning vCJD and BSE.

4. Steps taken to make SEAC more open; public summaries of meetings published by SEAC.

5. Professional bodies set up to give independent advice:

SEAC (1990)

SEAC human epidemiology sub-group
(1997)

SEAC/Advisory Committee on Dangerous Pathogens joint working group (1996)

Transmissible SPongiform Encephalopathy (TSE) research Advisory Group (1996)

TSE research Funders' Group (1996)

6. £200m to modernise NHS decontamination facilities announced 4 January 2001. On same date the introduction of single-use instrumjents for tonsillectomy during 2001, at an extimated cost of some £25m, was announced.

Elephant traps (*If applicable*)

(Elephant Traps are not published on the Departmental Intranet. If no formal rebuttal document exists please indicate the areas of this policy area which are potential areas of criticism and the line to take should these be raised. If a formal rebuttal document does exist a document link to the relevant rebuttal should be included in the related document field below. Please see the help file if you are unsure how to carry out this operation)

1. Tonsil single use instruments not yet available - supplies coming on stream; should be near normal by the summer. DH - with support from BAO - has not advised that all tonsil surgery should cease. Cases where there is clear clinical need should still proceed.

2. Why not brain /back of eye surgery also single use when likely to be higher risk - decontamination is key; single use is second to that. Taking steps to ensure instruments used for such operations are processed by centres where the best decontamination facilities are located. Brain surgery being looked at for possible single use, but position far from straightforward; more life-threatening conditions being addressed than for tonsillectomy; cannot compromise immediate clinical outcome through use of untried instruments.

3. My child had tonsils out using reusable instruments and now at risk? - theoretical risk; cannot quantify it. Government acting on precautionary basis. Have to keep a sesne of proportion and remember that operations themselves are not risk-free eg through anaesthetic.

4. Could have prevented risks to human health if more stringent action taken to eliminate disease in cattle and on beef and beef products at start of BSE epidemic - we did everything that seemed necessary at the time in the light of existing knowledge and scientific advice; controls on beef and beef products tightened up as scientific knowledge advanced and failures came to light.

5. Action tempered by fear of damage to food industry - the protection of public health is

paramount but need to balance level of risks addressed against harm caused by action to other parties

6. DH dominated by MAFF - SEAC provides independent advice; CMO is CMO of both Departments

7(a). Hundreds of thousands could die - the long term projected number of vCJD cases remains unclear. The work of the human epidemiology sub-group and the surveillance work carried out by CJDSU may in due course shed some light on these questions.

(b). Human epidemic will be very small and the measures to protect public health have been excessive and unnecessarily damaged the beef industry - due to lack of information it is not possible to make any assumptions about the parameters of the epidemic and forecasts of future numbers of cases, large or small, cannot be made with any confidence. While this situation prevails we must take whatever action seems necessary to protect public health.

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